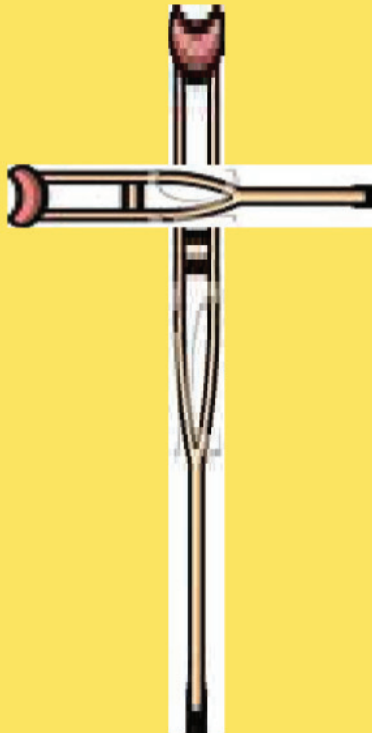


Disability, Society, and Theology

Voices from Africa



Edited by
Samuel Kabue
Esther Mombu
Joseph Galgala
C. B. Peter

VISIT...

LANZAROTE
Caliente.COM

Disability, Society and Theology

Zapf Chancery Tertiary Level Publications

A Guide to Academic Writing by C. B. Peter (1994)
Africa in the 21st Century by Eric M. Aseka (1996)
Women in Development by Egara Kabaji (1997)
Introducing Social Science: A Guidebook by J. H. van Doorne (2000)
Elementary Statistics by J. H. van Doorne (2001)
Iteso Survival Rites on the Birth of Twins by Festus B. Omusolo (2001)
The Church in the New Millennium: Three Studies in the Acts of the Apostles by John Stott (2002)
Introduction to Philosophy in an African Perspective by Cletus N. Chukwu (2002)
Participatory Monitoring and Evaluation by Francis W. Mulwa and Simon N. Nguluu (2003)
Applied Ethics and HIV/AIDS in Africa by Cletus N. Chukwu (2003)
For God and Humanity: 100 Years of St. Paul's United Theological College Edited by Emily Onyango (2003)
Establishing and Managing School Libraries and Resource Centres by Margaret Makenzi and Raymond Ongus (2003)
Introduction to the Study of Religion by Nehemiah Nyaundi (2003)
A Guest in God's World: Memories of Madagascar by Patricia McGregor (2004)
Introduction to Critical Thinking by J. Kahiga Kiruki (2004)
Theological Education in Contemporary Africa edited by Grant LeMarquand and Joseph D. Galgalo (2004)
Looking Religion in the Eye edited by Kennedy Onkware (2004)
Computer Programming: Theory and Practice by Gerald Injendi (2005)
Demystifying Participatory Development by Francis W. Mulwa (2005)
Music Education in Kenya: A Historical Perspective by Hellen A. Odwar (2005)
Into the Sunshine: Integrating HIV/AIDS into Ethics Curriculum Edited by Charles Klagba and C. B. Peter (2005)
Integrating HIV/AIDS into Ethics Curriculum: Suggested Modules Edited by Charles Klagba (2005)
Dying Voice (An Anthropological Novel) by Andrew K. Tanui (2006)
Participatory Learning and Action (PLA): A Guide to Best Practice by Enoch Harun Opuka (2006)
Science and Human Values: Essays in Science, Religion, and Modern Ethical Issues edited by Nehemiah Nyaundi and Kennedy Onkware (2006)
Understanding Adolescent Behaviour by Daniel Kasomo (2006)
Students' Handbook for Guidance and Counselling by Daniel Kasomo (2007)
Business Organization and Management: Questions and Answers by Musa O. Nyakora (2007)
Auditing Principles: A Students' Handbook by Musa O. Nyakora (2007)
The Concept of Botho and HIV/AIDS in Botswana edited by Joseph B. R. Gaie and Sana K. MMolai (2007)
Captive of Fate: A Novel by Ketty Arucy (2007)

(Continued at the end of this book)

Disability, Society and Theology

Voices from Africa

Edited by

Samuel Kabue, Programme Executive, Ecumenical Disability
Advocates Network (EDAN), Nairobi, Kenya

Esther Mombo, Associate Professor and Deputy Vice Chancellor
(Academic Affairs), St. Paul's University, Limuru, Kenya

Joseph Galgalo, Associate Professor and Vice Chancellor,
St. Paul's University, Limuru, Kenya

C. B. Peter, Senior Lecturer, St. Paul's University, Limuru, Kenya



Zapf Chancery
Limuru, Kenya

First Published 2011

© Authors

All rights reserved.

Cover Concept and Design

C. B. Peter

Associate Designers and Typesetters

Nancy Njeri and Esther Mwangi

Copyediting

C. B. Peter, Phyll Chesworth, and Ben Shiholo

Publishing Consultant

C. B. Peter

Printed by

Kijabe Printing Press,

P. O. Box 40,

Kijabe.

Published by



Zapf Chancery Publishers Africa Ltd,

C/o St. Paul's University

P. O. Box Private Bag - 00217

Limuru, Kenya

0721 222 311

zapfchancerykenya@yahoo.co.uk

*This book has been printed on
fully recyclable,
environment-friendly paper.*

ISBN 978-9966-7341-7-4

Foreword

Dr. Dietrich Werner

In the key study document “A Church of all and for all” which was published by WCC in September 2003, it was stated: “It is estimated that some 600 million people are persons with disabilities. Yet people, especially persons with disabilities, still find themselves isolated. Now there are walls of shame; walls of prejudice; walls of hatred; walls of competition; walls of fear; walls of ignorance; walls of theological prejudice and cultural misunderstanding. The Church is called to be an inclusive community, to tear down the walls.”

The Ecumenical Disability Advocates Network (EDAN) which is a project of the WCC within the Unity, Mission, Evangelism and Spirituality Programme, established after Harare Assembly in 1998, has done a magnificent work to create more awareness on disability issues in all major parts of the world. Under the committed and competent leadership of Mr. Samuel Kabue, EDAN Coordinator from Nairobi, this collection of essays and key articles on Disability, Theology and Society from African perspectives is a long awaited and needed resource book to deepen and further insights of the foundational paper “A Church of all and for all”. It provides a comprehensive and broad based new Handbook to enrich and inform courses on disability issues in theological education all across Africa and beyond.

The papers and articles published here which come from the earlier workshop in St. Paul's University, Limuru, Kenya in June 2008 complement earlier workshops and resources published on Doing Theology from a Disability Perspective in Asia.¹

Teaching theology from Disability Perspectives has become a major concern and is firmly established now also in the international discourse of theological education which is facilitated by the Programme on Ecumenical Theological Education (ETE) of WCC.²

The disability discourse has a profound relevance both for proper contextualization of the theological education and for the relation of theological education to the unity of the church³ which for decades have been key concerns for the ETE Programme of the WCC.

On behalf of the ETE Programme we congratulate the editors and all contributors for making available this impressive resource book hoping that curriculum plans for courses on Disability Theology

¹Wati Longchar/Cowans Gordon (ed), *Disabled God Amidst Broken People : Doing Theology from Disability Perspective*. Manila, ATESEA 2006.

²Dietrich Werner, David Esterline, Namsoon Kang, Joshva Raja (eds): *Handbook of Theological Education in World Christianity. Theological Perspectives, Ecumenical Trends, Regional Surveys*. Regnum Books International 2010, see particularly: Samuel Kabue: *Disability Discourse, Theological Education and the Journey of EDAN*, p. 230ff

³See the reference document and global study report on theological education: *Challenges and Opportunities in Theological Education in the 21st Century*. Pointers for a new international debate on Theological Education, ETE/WCC November 2010; see also: <http://www.oikoumene.org/en/resources/documents/wcc-programmes/education-and-ecumenical-formation/ecumenical-theological-education-ete/edinburgh-2010-international-study-group-on-theological-education.html>; short version on: http://www.oikoumene.org/fileadmin/files/wcc-main/documents/p5/ete/E2010_summary_World_Study_Report11_2009.pdf

like the one from St. Paul's University by Esther Mombo and Joseph Galgalo documented at the end will find wider circulation and will make real impact in the theological teaching in all African universities and colleges dealing with ministerial formation and broad based theological education. It has been a privilege for ETE to accompany and to support this process.

Christ came to tear down the walls (Eph 2:14). Still there are many walls for people with disabilities that shut people in or shut people out; walls that prevent people from meeting and talking to others. The WCC study had reminded us, that all of these walls are so human, yet they fundamentally contradict Christ's ministry of reconciliation. It is a sign of hope therefore that the vision is renewed again, that the walls which are set up in society, in churches, in culture or the human mindset to keep with people with disability outside will be overcome and torn down. That is the vision which is embodied and expressed again in the articles of this book. That is the vision which also should accompany the wider distribution and reception of this unique African resource book on disability theology.

Dr. Dietrich Werner
Global Programme Coordinator
Programme on Ecumenical Theological Education (ETE)
World Council of Churches, Geneva

Introduction

This volume is part of a series of disability study materials development process in response to a need identified after the introduction of a disability studies in the curriculum of a number of theological institutions through the initiative of the Ecumenical Disability Advocates Network (EDAN). The first in the series were two volumes produced in 2007 through a joint project of Ecumenical Theological Education (ETE), EDAN and Association of Theological Education Institutions in South East Asia (ATESEA). Volume one is entitled: *Persons with Disabilities in Society: Problems and Challenges* and the Second volume is *“Disabled God amidst Broken People”*.

“Disability, Society and Theology: Voices from Africa” is the result of a workshop which brought together African theologians, persons with disabilities and disability expertise in the Region to prepare resource materials to enrich the disability study process in the context of the Africa region. The workshop was organized in Mombasa Kenya in June 2008 under the joint leadership of EDAN and Saint Paul’s University Faculty of Theology. The writers were drawn mainly from Theologians, persons with disabilities and disability experts from the African Region. Each of the writers was given a topic to research on and prepares a paper in accordance with his or her expertise and experience. At the end of the workshop, twenty-four papers was presented, critically analyzed and the writers given time to go back and improve on them. An Editorial committee

was formed to put the papers together and the result of all this work was the publication of this volume.

**Samuel Kabue,
Executive Secretary, EDAN**

Contents

<i>Foreword</i>	v
<i>Introduction</i>	viii
<i>Abbreviations</i>	xv

Part One: Disability Theology: Issue to Debate

Chapter One: Persons with Disabilities in Church and Society: A Historical and Sociological Perspective (<i>by Samuel Kabue</i>)	3
Chapter Two: Claiming and Developing a Disability Hermeneutics: Towards a Liberating Theology of Disability (<i>by Arne Fritzon</i>)	25
Chapter Three: Perfect God and Imperfect Creation: In the Image of God and Disabled (<i>by Joseph D. Galgalo - St. Paul's University</i>)	31
Chapter Four: Sin, Suffering, and Disability in God's World A. (<i>by Wati Longchar</i>)	47
Chapter Five: One in Christ: Priesthood of the Disabled and the Exercising of Gifts (<i>by C. B. Peter - St. Paul's University</i>)	59
Chapter Six: Biblical Perspectives on Disability (<i>by Sammy Githuku - St. Paul's University</i>)	79

Part Two: The Able Disabled and the Disabled Church: The Church's Response to Disability

Chapter Seven: Lazarus Come Out! How Contextual Bible Study can Empower the Disabled (<i>by Janet Lees</i>)	97
Chapter Eight: The Church, Public Policy and Disability Concerns in Kenya (<i>by Phitalis Were Masakhwe</i>)	111
Chapter Nine: Cultural Barriers to the Disabled People's Participation in Church Life (<i>by Reuben Kigame</i>)	121

Part Three: Disability and Society

Chapter Ten: Education, Employment, and Health: A Disability Perspective (<i>by Anjeline Okola</i>)	141
Chapter Eleven: Society and Leadership: Challenges and Opportunities for People with Disabilities (<i>Esther Mombo - St. Paul's University</i>).....	157
Chapter Twelve: Disability: Social Challenges and Family Response (<i>by Joseph Shiriko</i>).....	169

Part Four: Disability Theology: Some Interfaces

Chapter Thirteen: Disability and Sexuality (<i>by Salome Wairimu Muigai</i>).....	199
Chapter Fourteen: Gender and Disability Challenges within the Church (<i>by Joseph Sinyo</i>)	209
Chapter Fifteen: Combating HIV & Aids among Persons with Disability: A Disability Perspective (<i>by Paul Chappell</i>)	221

Part Five: Disability and Caregiving

Chapter Sixteen: Persons with Disabilities and Psychological Perspectives (<i>by Ndung'u J. B. Ikenye - St. Paul's University</i>).....	245
Chapter Seventeen: Psychosocial Disability: Attitudes and Barriers to Social Integration in Church and Society (<i>by Jane Amegatcher</i>).....	275
Chapter Eighteen: The Church and Pastoral Counseling for Disability (<i>by David Kiarie</i>)	297

Part Six: Disability in the African Experience

Chapter Nineteen: Persons with Disabilities in Madagascar (<i>by Ralphine Razaka</i>)	315
Chapter Twenty: Persons with Disabilities in Malawi: What are the Issues? (<i>by Rachel Kamchacha Kachaje</i>)	337
Chapter Twenty One: A Profile of Tanzanians with Disabilities (<i>by Kaganzi Rutachwamagyo</i>)	363
Chapter Twenty Two: Persons with Disabilities in Uganda (<i>by Gidudu Balayo N. Seezi</i>)	383
Chapter Twenty Three: Persons with Disability in South Africa (<i>by Joy Sebenzile P. Matsebula</i>).....	403
Appendix	427
Bibliography	431
Contributors	449
Index	453

Abbreviations

ADD	-	Action on Disability and Development
Aids	-	Acquired Immune Deficiency Syndrome
APT	-	Appropriate Technology
CBR	-	Community Based Rehabilitation
COMBRA	-	Community Based Rehabilitation Alliance
CSOs	-	Civil Society Organisations
CWDs	-	Children with Disabilities
DPOs	-	Disabled Peoples Organisation
ESA	-	Epilepsy Support Association
HIV	-	Human Immune Virus
LAB	-	Labour Advisory Board
MGLSD	-	Ministry of Gender Labour and Social Development
MHU	-	Mental Health Uganda

MOE	-	Ministry of Education
MoH-PR	-	Ministry of Health – Disability Prevention and Rehabilitation
NAADS	-	National Agriculture Advisory Services
NUDIPU	-	National Union of PWDs of Uganda
NUSAF	-	Northern Uganda Social Action Fund
NUWODU	-	National Union of Women with Disabilities of Uganda
PWDs	-	Persons with Disability
SNE	-	Special Needs Education
TASO	-	The Aids Support Organisation
UBC	-	Uganda Broadcasting Corporation
UHRC	-	Uganda Human Rights Commission
UNAB	-	Uganda National Association of the Blind
UNAD	-	Uganda National Association of the Deaf
UNAPD	-	Uganda National Action on Physical Disability
UNISE	-	Uganda National Institute of Special Education
UPACLED	-	Uganda Parents Association of Children with Learning Difficulties
VIS	-	Visually Impaired Students
WWDs	-	Women with Disabilities

CHAPTER ONE

Persons with Disabilities in Church and Society: A Historical and Sociological Perspective

Samuel Kabue

Introduction

I was once invited to address Bible School final year students on the subject of persons with disabilities (PWDs) in church and society. I began my address with a rhetorical question as to whether it was worth the effort to reach out to PWDs with the gospel. The answer was as expected “yes”. What else could I have expected from these future pillars of the church just about to begin their theological careers especially when I myself was a person with a disability? Their training was based on the premise that “God is no respecter of persons”. After all, I was told, even the PWDs are created in the image of God. This is a very easy concept at the academic level. As I continued my interaction with these students, I wondered whether they really understood who PWDs were. As they shared their own experiences, it became clear (even to them I suppose) that, the reality on the ground was different.

They agreed that participation in the social and spiritual development of the society and church by PWDs is certainly wanting. However, they were not sure what could be done about it. This chapter explores PWDs in church and society from a historical setting, personal experience, and point of view. It gives a short

explanation on who the PWDs are, discusses the historical background and outlines specific sociological experiences.

Who are PWDs?

For the last twenty years, the terminology and definitions used to refer to the categories of the people considered in this discussion have been the subject of an ongoing debate among academicians, health professionals, social workers and the disability movement. The term “disability” is a creation of the modern society in its attempt to group people with different characteristics. It is not a term that existed either in the Western or the African traditions.

The Judeo-Christian tradition too did not have this type of classification. It described individuals in accordance with their specific infirmities. This explains why the term is not found in the Bible. The term emerged in an attempt to have organised care for people who in the eyes of the society were seen to require care and attention. The earliest definitions of the term were therefore given by caregivers.

Arguments over definitions have intensified with the emergence of new players in the field. Thus, disability has been defined in different ways at different times and by different categories of people. These definitions reflect different interests and understanding depending on who is defining disability. The definitions fall into two main categories: the medical model and the social model. Caregivers, health care workers and academics have largely embraced the medical model while PWDs through their movements are largely proponents of the social model.

Below are typical definitions based on the medical model, as proposed by the World Health Organisation (WHO) from as far back as 1980.

Impairment – any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability – any restriction or lack, resulting from an impairment of ability to perform any activity in the manner or within the range considered ‘normal’ for a human being.

Handicap – a disadvantage for a given individual, resulting from an impairment or disability, that prevents the fulfillment of a role that is normal depending on age, sex, social and cultural factors for that individual.

The emergence of fresh thinking and new organisations controlled by PWDs themselves and their struggle against segregation resulted in a careful re-working of the set of definitions – similar to those of WHO. These definitions as stated below were seen as a direct challenge from people with disabilities.

Impairment – lacking all or part of a limb, or having a defective limb, organ or mechanism of the body.

Disability – the disadvantage or restriction of activity caused by contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

The political significance of these definitions lies in the fact that:

- (a) they are a statement coming out of the direct experience of disability;
- (b) that they place the cause of disability fairly and squarely with society;
- (c) that they separate and sharpen the distinction between the individual and the environment in which he or she interacts;
- (d) that they are a tool for measuring the role and relevance of existing service systems;
- (e) that they depict disability positively as a phenomenon which can be overcome; and
- (f) that they lift the veil which obscures the ugly face of discrimination against PWDs in contemporary society.

PWDs believe that there is a hidden political purpose behind the definitions by caregivers – to justify their occupation and thinking. Politicians and academics support the definitions by caregivers because they rely on them (caregivers) for advice. Also, people with disabilities' movements, as social groups face an important political task. They have to take control and determine the way their situation is described and defined. A common prevailing view among PWDs especially in Britain and Western Europe is that the caregivers' definitions emphasise the cause of the problem(s) PWDs face in their individual impairments. As long as caregivers put emphasis on the notion that it is the bodies of those with disabilities that are at fault, the negative structures in society that stigmatise PWDs will continue to persist. By simply focusing on the body, the definitions draw attention away from the discriminatory nature of society. Such definitions underpin the hegemony of ideas caregivers have constructed to justify their argument.

In the ecumenical circles, descriptions have moved from theological reflection to practical questions of inclusiveness within churches and church communities. Terms such as "persons with handicaps" and "the differently abled" and "persons with a disability" have been used at different times and have been usually designed to reflect inclusiveness and are used interchangeably. The term "the differently abled" was used over a long time at a certain stage of the World Council of Churches (WCC) work on disability. It was discarded because it was only understood within the ecumenical family and especially in churches and organisations closely related to WCC. It is a term that is resented by PWDs who argue that who pose the question, who in this case is not "differently abled" in the entire world population? And if we all are, who then does the term refer to? There is still a lot of hung over on it among some groups within the ecumenical family. However, the terms in current use at the WCC since 1997 are "persons with disabilities" or "people with disabilities". With the unfolding interpretation and understanding of disability by different persons, these terms are already considered inappropriate if not controversial. Perhaps this is as it should be in

order to encourage on-going discourse which could lead to deeper understanding of the essence behind different meanings.

In Kenya, the term disability has two important definitions. The Persons with Disability Act, 2003, defines disability as:

a physical, sensory, mental or other impairment, including any visual, hearing, learning or physical incapability, which impacts on social, economic and environmental participation.

The Draft Constitution of Kenya 2004 however, defines disability as including

any physical, sensory, mental, psychological or other impairment, condition or illness that has, or is perceived by significant sectors of the community to have, a sustainable or long-term effect on an individual's ability to carry out day-to-day activities.

The difficulties in defining the term disability in the recent past has greatly intensified with promulgation of various statutes in different countries where such legislations are used to determine who receives services provided under such statutes. The difficulty lies in ensuring that a definition adopted does not leave out a section of people that it should otherwise cater for. The process of the promulgation of the UN Convention on the rights of persons with disabilities was greatly influenced by the quest to ensure that no one who should be included was left out. In the process, the ad hoc committee which worked on the convention chose to play safe by avoiding a definition but instead, they provided in Article 1 on the purpose of the convention that:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Historical Background

The historical path towards the understanding, acceptance and integration of PWDs in church and society has been a long one. We still cannot say with certainty that much has been achieved in regard to their spiritual and social liberation. However, after virtually centuries of misunderstanding, discrimination and downright paternalistic care, a dim light through the dark tunnel has begun to bring about a sign of hope in form of the prevailing good will. Churches have begun to be sensitised to view PWDs not just as people who only need physical and material help but as full members of the human family who like all of God's people also require spiritual care and nourishment.

In the early days when man lived on hunting and gathering, there was no place for PWDs. Life was based on survival for the fittest. With the discovery of farming, the welfare for PWDs begun because there was surplus food to be shared. Subsequently, the extended largely agricultural families that were common until the industrial revolution accommodated a good number of PWDs. Other PWDs were taken into convents and monastic infirmaries where their bodily survival needs and care were met though with no reference to their spiritual needs. Obviously, some of the less fortunate ones were treated inhumanly and often abandoned in streets where they were objects of ridicule.

Even in the later part of human history, the situation remained different in different cultures. In some, infanticide was widely spread. Plato stressed the association of disease with moral imperfection and evil. Among the Greek City states like Athens and Sparta, the common practice was that everybody in the society had to train to be a soldier. To them, a healthy spirit deserved a healthy body. There was no room for weaklings and PWDs were therefore rarely allowed to survive. At some point in history, especially from the time of early Greeks and Romans into the Middle Ages, PWDs were a source of humour. People with mental impairments were kept by the royal courts for entertainment. Court jesters might have had a physical deformation, yet could perform feats such as

acrobatics and juggling. Entertainment was a rare path to independence for a person with a disability, at a time when the only other option were to be a beggar or a burden to one's family. Some entertainers even gained privileged household positions. The Roman Empire proved to be a short-lived period of employment opportunity for someone with a disability. In 235 AD Emperor Alexander Severus banished all such individuals from Rome. Once, court fools wandered the empire, resorting to performing or begging in the streets of the cities for survival.

For much of human history in Western societies, a person with a disability was considered a burden to others – a drain on resources who put nothing back. A family's sense of honour was thought to be compromised by the presence of a person with a disability. They would be spurned by the community. The expense and time of providing for a disabled member would reduce the family's ability to live up to community standards. There was great pressure to institutionalise a person with a disability (once this option even existed), to allow death from an illness, or even end his life by euthanasia.

Such perceptions of disability and attitudes to PWDs are by no means unique to any parts of the World. Many ancient cultures even endorsed methods of infanticide to deal with the 'problem' faced by having children born with disabilities. Ndurumo (1993) has shown how depending on the ancient cultural beliefs and practices, the fate of disabled children in African societies could be adverse. Life could be short-lived and in many cases, at best, inhospitable. In some of the societies, the presence of disability at birth was often considered to be reflective of a broken relationship between the family and God. Often "the child was killed and sent back to God so that He might send another child without disability. Such children were killed with the full approval of the community and the question of infanticide never arose" (Ndurumo, 1993:3).

Suffice to say that cultural responses to people with perceived impairments are by no means universal. Whilst there are several examples of cultures which accommodate the needs of so called

disabled people, there are others which do not. Moreover, although infanticide for children with visible impairments has consistently characterised western and African cultural development, it is evident that such people have existed throughout recorded history. There are several reasons for this. Notably, human beings are not simply cultural dupes. It is likely, therefore, that many parents rejected such practices and supported their disabled offspring. Also, the overwhelming majority of impairments are acquired rather than congenital; either through accident, illness or, simply, old age. Thus, ensuring that the experience of impairment was and is a common rather than an exceptional occurrence. This was certainly the case in the Graeco/Roman world where life was extremely harsh for all but the most privileged – high born, well-to-do males in perfect health.

However, in contrast to those who see a problem where there is none, it is an attempt to provide a clear and understandable focus on that which can and should be changed. Specifically, a value system which is rooted in a particular type of society, which is clustered around a particular view of the human condition, and which, in one way or another, oppresses all those who are unwilling or unable to conform to its requirements.

It needs to be noted that historical accounts of disability are rare and those that exist are written from varied viewpoints. Those written by PWDs especially in the recent past argue that the social environment in which PWDs live is the major problem that makes their lives difficult. It is not, they aver, the impairments that have brought about their perceived disabilities. The quest for participation underlies such writings. Vic Finkelstein (1980) argues that disability is the direct result of the development of western industrial society. Using a largely materialist analysis Finkelstein divides history into three distinct sequential phases. Phase One broadly corresponds to the feudal period which preceded European industrialisation. Here economic activity consisted primarily of agrarian or cottage based industries, a ‘mode of production’, he maintains, which does not preclude people with perceived impairments from participation. But in Phase Two, in the nineteenth century when industrialisation took

hold, people with impairments were excluded from employment on the grounds that they were unable to keep pace with the new factory based work system. Hence, they were segregated from the mainstream of economic and social activity into a variety of residential institutions. Finkelstein's Phase Three, which he maintains is only just beginning, will see the eventual liberation of disabled people from such oppression through the development and use of technology, and their working together with helpers and allies towards common goals.

For Finkelstein, therefore, disability is a paradox emerging out of the development of western capitalist society. On the one hand, disability implies 'a personal tragedy, passivity and dependence' (Finkelstein, 1980). On the other, it can be seen as a societal restriction and discrimination. In Phase One, people with impairments were dispersed throughout the community; but in Phase Two due to the emergence of large scale industry with production lines geared to 'able bodied norms' and 'hospital based medicine', they were separated from their social origins into a clearly defined devalued group. Phase Three will witness the end of the paradox as disability will be recognised as social restriction only.

Although intended as an aid to understand rather than an accurate historical statement, Finkelstein's analysis has been criticised for being over-optimistic. It is over-simplistic in that it assumes a simple relationship between the mode of production and perceptions and experiences of disability. It is too optimistic in its assumption that technological development and professional involvement will integrate disabled people back into society.

Early Church's Experience

Throughout history, disabilities have been commonly seen as acts of a vengeful God. In a world in which real or imagined sin abound, the emergence of a child with a disability in a family was regarded as a punishment for sin. This common social belief clearly manifests itself in the Jewish cultures as expressed in the Old Testament, depicting disability as divine retribution for sinful behaviour as

expressed in Leviticus 21:17, “Whosoever that hath any blemish, let him not approach the altar to offer the bread of his God.” We see the same belief in the Gospel according to Saint John 9:1-3. In this passage, Jesus was faced with a question from his disciples in connection with a man who was blind since birth; “teacher, who sinned, this man or his parents that he was born blind?” In his answer, Jesus exonerated both the blind man and his parents (verse 3). “It is not that this man sinned, or his parents but that the works of God might be made manifest in him”. This message is yet to reach the majority of those concerned, their families and a great section of the church. It has also not been given enough impetus to sink into the thinking and theology of the church. All the same, in Judeo-Christian culture, children with disabilities were at least permitted to live.

During the Middle Ages, another notion about disability was considered. Perhaps a disability was not punishment from God but an expression of evil through the devil. At the same time, the Christian church developed some charitable motives, in particular for the blind and amputees. The Crusades (beginning in 1096 AD) ensured a steady supply of these victims—the only kinds of disability likely to survive the traumatic injuries of war. Traumatic injury such as spinal cord compression, birth defect, polio and other diseases were far more likely to be fatal, so did not add to the population of the disabled. The most visible and feared of medieval cripples were lepers, perhaps because the concept of contagion attached itself to the disease early on, or because it can cause blindness, amputation, and other conditions.

Lepers were kept out of city walls, and forced to gather in isolated colonies. Leprosy reached epidemic proportions in the 13th and 14th Centuries, with 19,000 leprosariums in Europe by the year 1200 AD. In 1321 in France a rumour spread that lepers plotted to poison the waters. This was never proven, but King Philip V ordered that:

To cleanse the earth of the criminal and superstitious leprous fester, lepers and Jews alike should die in purifying flames.

This was possibly the worst mass murder prior to Adolph Hitler. Life with disability got worse as Europe, North Africa, and the Near East were ravaged by plagues. In response, statutes evolved in mid-14th century England regarding vagrants and beggars who were feared as plague carriers.

A person's value at this time was based on his ability to work. A 1349 AD English law read:

Because many beggars, as long as they may live of begging, do refuse to labour, giving themselves to idleness and vice, and sometimes to theft and other abominations; none shall under the colour of pity or alms, give anything to such, which may labour so that thereby they may be compelled to labour for their necessary living.

What had just become a matter of Christian charity was now forbidden in the interest of wage labour, a system just emerging at the time. In effect, those who were disabled were branded as thieves and wastrels. Society would not bear the burden of caring for them. Those thought able to work might easily have been sent off to the galleys as slaves.

Other laws defined boundaries within which beggars would be allowed to function. In 1531 England, Henry VIII's parliament segregated PWDs in separate districts, and later attempted to restrict alms-giving to undesirable vagrants while allowing "lepers and bedridden creatures" to receive of the public good will.

Monasteries in medieval Europe were willing to accept a number of needy souls within their walls as servants or even as monks. In one case, Pope Gregory XIII charged the Arch Confraternity of the Holy Trinity for the Care of Pilgrims and Convalescents with clearing all beggars from the city. Those truly able-bodied were sent away to work for their livelihood; the truly crippled and unable to work

were to be maintained in the monastery of Saint Sistro. But when 850 cripples were quickly collected and taken to the monastery, Gregory's plan was swiftly cancelled, and Rome was again filled with "importunate and clamorous beggars" according to Compton.

Charity hospitals were also invented in the Middle Ages. Hardly a place of treatment, much less rehabilitation, they functioned as nightmarish storehouses. The number of beggars continued to rise. The numbers on the streets in 17th century Paris became so severe—as many as 40,000—that the founding of a general hospital to deal with them barely made a dent. Other ideas began to take form. One 'creative' suggestion was to locate deformed persons near the blind who would not be offended by them.

The Church in Modern Times

Measured against the standards of the time, the church was a virtual pioneer in the care of PWDs. It has continued to play this role alongside the governments and other modern charities. However, there still remains a big question as to how the church has treated PWDs in regard to spiritual care as compared to other needs. Too many assumptions have been made about PWDs spiritual state based on an attitude, which can be referred to as a "a spread phenomenon". This is characterised by the tendency to draw inferences about a person based on the loss of an obvious functional ability. For instance, the fact that a person does not see, walk or hear leading to the assumption that he is not capable of committing sin. Disability is in this case assumed to play down not only on one's general health but also one's natural emotions. Whereas a weak body, a feeble mind or a sensory disability is easily noticeable, this is not so with a weak spirit. Measures are usually attempted to compensate these other physical or sensory disabilities but the soul which might even be easier to put right is either forgotten or ignored all together. The emphasis on the physical dysfunction has often erroneously made PWDs feel that their state of being will cause them remission of sin.

In the past, the lives of PWDs have been spent within conditions of regulated care, mistaken theology and misguided notion of charity. This has been characterised by “caging” them especially in their formative stage in segregated institutions for a long time, bringing about the idea that they are special and different from the rest of society.

The result has been spiritual and social alienation of these from the rest of society. The evidence to this situation is the fact that up to the present time, very few churches are accessible to PWDs. Those that permit entry deny further accessibility. A fully accessible church should permit the PWDs access to the sanctuary so that they are able to participate in all aspects of the church activities. Fully accessible churches should have programmes for intellectually impaired, some sign language interpreters for the deaf, sitting that can permit wheelchair users to sit with their families and should also assign Sunday readings to blind readers who can read Braille and are willing to do so as a way of encouraging participation. It may be rightly argued that not all congregations can afford these facilities but at least the majority of churches should feel challenged about it.

The situation up to now is that pastors and evangelists do not see the PWDs because they do not go to the churches and congregational meetings. The reason why they do not go to these places is either because they cannot get in or cannot participate if they get there. I am reminded of a hearing impaired friend who approached a pastor after a church service and said: “Pastor, I understood nothing of what you said”. The pastor retorted, “Do not worry, God knows that you are deaf”. My friend left the church very disappointed as he expected a better solution to this problem but which he realised that he could not get. The deaf are not an exception when the Bible says in Roman 10:13-15: “For whosoever shall call upon the name of the Lord shall be saved. How then shall they call on him in whom they have not believed? And how shall they believe in him of whom they have not heard and how shall they hear without a preacher?”

For reasons like the example of my friend above and many others, the PWDs stay away from the church and pastors think that they do not have disabled people in their parishes. It is an established fact that 10% of the population within a catchment area of any parish is made up of PWDs of one type or other. Very often their families do not go to church either. The preparation for eternal life in which our bodily infirmities and other forms of suffering shall be no more calls for opening of doors for all souls by reaching them with the word of God. It does not matter the cost at which this has to be done. Faith has to be created in the hearts of people irrespective of their bodily infirmities since these have no relevance to eternal life. The Bible says again in Romans 10:17, "So then, faith cometh by hearing and preaching the word of God". The church therefore has a duty to reach the PWDs as well as their entire families lest their souls should be lost on account of having not been reached with the gospel.

Social Participation

It has to be borne in mind that it is not just in realm of spiritual needs that the PWDs have received discouragingly separate treatment. They have also not been involved in other social development activities within the church and community in general. The spiritual negligence is only a part of this trend. It is common knowledge that PWDs constitute one of the most marginalised and impoverished groups within the society, a fact that most organisations agree in principle. PWDs are more likely to be uneducated, unemployed, lack access to health care, vulnerable to abuse and socially marginalised. The church should see itself as the most authentic institution to champion the cause of forging an equal partnership with the PWDs. It is the most legitimate door to participation of PWDs in spiritual, social and development activities in the community. Equal partnership has to be based on the fact that PWDs are not an exception in the society. Rather they are the rule as they have always been. Jesus defined his mission on earth by reference to the PWDs. When asked by John's disciples if he was the Messiah, he said "Go and tell John what you

hear and see: the blind see again, the lame walk, lepers are cleansed, the deaf hear and the dead are raised to life and the good news is proclaimed to the poor” (Mathew 11:4-5). This inclusion of all people by Jesus in his work is a sign of his special message to restore the human condition to wholeness. The church is expected to follow this example and to do all that is within its means, not as an option but as a commission by Jesus Christ.

PWDs have been misunderstood, overlooked and sometimes discriminated for too long. The biggest obstacle to their meaningful inclusion into mainstream community life is negative public attitudes. These range from overt prejudice and hostility, condescension and pity to ignorance and indifference, and in these diverse ways they influence how we think about both ourselves and other people. In the broadest sense there are two explanations for this phenomenon. The first, and the older of the two, suggests that cultural perceptions of impairment are shaped by deep rooted psychological fears of the abnormal and the unknown. The second explains disabled people’s oppression in terms of material considerations such as the economy and the way that it is organised or what is sometimes termed the mode of production.

In the recent past, the secular world has slowly been taking up the concept of mainstreaming disability as one way to combat the old age tradition of separate treatment of disability concerns. Broadly, mainstreaming refers to a strategy through which concerns, needs and experiences of disabled people are made an integral part/dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres, so that disabled people benefit equally and inequality is not perpetuated (Albert, 2005). The hitherto residual treatment of disability as only a social welfare issue, it was realised, would not lead to emancipation or equality; it was perceived that mainstreaming issues of disability within the broader development agenda was the only viable/useful way forward.

Though the call for mainstreaming from Disabled People’s Organisations (DPOs) is not a new one, the last ten years has

witnessed significant efforts by development agencies and various governments adopting principles of mainstreaming at least within its policies. Subsequent to the adoption of the UN Standard Rules in 1991, United States Agency for International Development (USAID) formulated its disability policy in 1997 and the same was further made stronger in 2005. Since 2000 the Department For International Development (DFID) has also been attempting to mainstream disability into its policies. The European Union (EU) in 2003 came out with detailed guidelines encouraging its member states to mainstream disability in their international development agenda. The World Bank too demonstrated its commitment in this regard by setting up a disability and development team to encourage research and networking (Albert, 2005). The United Nations (UN) through its “Disability Dimension in Development Action: Manual on Inclusive Planning” lays out in detail how issues of disability can be addressed in mainstream development planning and programming.

WCC through the Ecumenical Disability Advocates Network (EDAN) is moving in the same direction by advocating for the inclusion, participation and active involvement of PWDs in spiritual, social, development and structural life of the church and society.

Despite such an impressive array of efforts, which undoubtedly demonstrates the novel intentions and realisation on the part of development agencies and governments regarding the approach to be embraced, studies and experiences on ground continue to bring out a degree of disconnect between policy and practice. This is therefore, an area in which a lot of work has to be done especially by the churches since they wield a huge influence in the society.

Three main cultural perceptions hinder PWDs from inclusion and participation in the church life: paternalistic and patronising attitudes, exclusion from participation and, an unjustified emphasis on physical healing. These have had negative consequences in the affairs of the general society as illustrated below.

Paternalistic and Patronising Attitude

When pastors and evangelists eulogise PWDs at church functions, they quite often say how cheerful the particular person is ‘in spite of his or her disability’. Most of the time, there is no reasonable cause for such a eulogy. The utterances only serve to magnify the presence of the disability ignoring other good attributes of the person and character. PWDs want such pastors to let them be human. They would like them not just to focus on their ‘disability’ when praising them but to help congregations to accept PWDs for their deeds and character and stop isolating them.

Closely related to this problem is the general assumption that PWDs are the same in their social behaviour, emotional maturity and sometimes even beliefs. Disability has nothing to do with an individual’s cognitive or affective processes. PWDs differ in personality and, we should not stereotype them. This is a tendency that has at times made PWDs complaisant about their state of being. Burdens of sins are not physical or sensory and cannot therefore be eliminated or even made less by physical or sensory disability. There should be no exception when the Lord says, “Come unto me all ye that labour and are heavy laden and I shall give you rest” (Mt. 11:28).

Exclusion from Participation

Church ministers, pastors and evangelists want to fulfil the Lord’s commission “Go ye therefore and teach all nations baptising them in the name of the Father and of the Son and of the Holy Ghost” (Mt. 28:19). There is however, inadvertent omission of adequately reaching out to and teaching the a large portion of the world’s 10% population which is disabled. There are various reasons for this state of affairs. Some of this can be identified as emanating from the human affective process. They include among others pity, fear and uneasiness. How do these interplay with our thinking? In general sense, pity has the idea of desperation and contempt. The person being pitied usually rejects it. In our case, it occurs when the pastors and evangelists equate PWDs with either general inferiority or

general inability of the person. There is often evidenced insinuations where these teachers of the word of God justify their failure to extend their invitation to PWDs to evangelical or church gathering on the assumption that they cannot, or will find it difficult to get to places of gathering. This is not always the case. In a family situation, the pastor will want to pray “for” the PWDs at home while s/he invites the rest of the family members to the gatherings. The negative aspect of pity becomes apparent when the teachers of the word insinuate that they are superior, all knowing and all caring.

Fear manifests itself in different ways. For instance, disabilities are seen by some as works of the devil and the presence of PWDs within the congregation is seen to reflect the inability of that church to combat the devil. One finds the disabled and avoids approach seeing them generally as not acceptable. The pastor would like to avoid any sign that would manifest spiritual weakness such as the evidence of the works of the devil as might be construed through the presence of people with infirmities in the congregation. The avoidance aspect, which is usually hidden from the conscious, is fought indirectly in various ways. This may sometimes be expressed by desperately invoking healing powers and designating as faithless those who do not get healed. Another dimension of fear is that of shying away from responsibility under the assumption or the perception that limitations of disability may make the anticipated relationship appear to carry with it an overwhelming burden which the church may be unwilling or unable to assume.

Uneasiness mainly emanates from the failure to relate with PWDs. The basis of uneasiness is usually uncertainty as to how to treat and to behave with a disabled person. Church ministers and others are often unable to act naturally with PWDs for three reasons:

- (a) their own complex about disabilities
- (b) their lack of understanding, and

- (c) their attention gets dominated with the idea of the presence of disability and the imagined limitations it imposes on that person.

They remain in the awkward position of wanting to help but being reluctant to ask the concerned person lest they are thought ignorant. To establish full understanding, fellowship and participation of PWDs in our churches, it is necessary to overcome such shortcomings.

Emphasis on Physical Healing

The Bible says: “For I am persuaded that neither death nor life, nor angels, nor principalities, nor powers, nor things present, nor things to come, nor height, nor depth, nor any other creature shall be able to separate us from the love of God which is in Christ Jesus our Lord” (Romans 8:39-39). Presence or absence of physical healing is no exception to these words of Paul, PWDs are no less created in the image of God and the state of their physical bodies does not in any way make them less deserving in terms of grace, honour and spiritual nourishment. It is alright if their physical suffering can be healed while they are still earth. However, this should not be made the principal purpose for presenting them before God. A good number of PWDs reject the church on the basis of embarrassment by preachers who assume that whenever a person with disability appears in a congregational gathering, he or she is seeking physical healing. In many charismatic meetings, people with disability will even be literally dragged to the front for prayers and will be designated faithless when such prayers do not take effect. These attitudes downplay the people with disability and their spiritual needs. The person is rarely seen as being in need of listening to the Word of God and is merely used to demonstrate individual preacher’s power of prayer. We need not in this respect lose sight of Paul’s experience when he testified in 2 Corinthians 12:7-9, “Unless I should be exalted above measure through the abundance of the revelations, there was given me a thorn in the flesh, the messenger of Satan to buffet me lest I should be exalted above measure (Verse 8). For this thing I sought the Lord thrice that it might depart from me. (Verse 9) And

he said unto me, my grace is sufficient for thee: then for my strength is made perfect in weakness. Most gladly therefore, will I rather glory in infirmities but the power of Christ may rest upon me”.

As stated in the WCC Interim statement on Disability, at the beginning of the 21st Century, as was the case before the Christian era, sectors of the population who are unable to compete or to perform at the levels that society demands are vitiated, despised or, in more contemporary terms, discarded. Among them, we find a high proportion of people with sensorial, motor and mental disabilities. We will find them living in any of the great cities of the world: men and women of all ages, ethnic backgrounds, colours, cultures and religions who, because they have a disability, live in abject poverty, hunger, dependence, preventable disease and maltreatment by those who are “able”.

It is the role of the church in this 21st Century to face the reality of humanity in the image of ‘a disabled Jesus’ on the cross; the reality of PWDs who are rejected and abandoned. It is painful that the churches throughout the world have not addressed more vigorously the sufferings of marginalised, poor, blind, deaf, and physically and mentally limited people. We do not need pity, or mercy, but compassionate understanding and opportunities to develop our vocations, possibilities and abilities.

In their efforts to attain peace, preserve the environment, ensure the equality of women and the rights of the child, care for the aged, churches and Christians should also include the struggle for the full realisation of disabled persons in their agenda.

Conclusion

Prejudice and discrimination create a cycle of disability, poverty and marginalisation. This cycle can only be broken if the issues raised in this chapter are confronted as matter of justice. Conscientious activists should be prepared to challenge the status quo in the spirit of disinterested love. This is the example of true living so eloquently spoken and demonstrated in the life of Jesus Christ. A call to Christ-like living is a call to disinterested love and

justice. It is a challenging call fraught with risk of opposition from the powerful and influential beneficiaries of the status quo. It is however not a call that can be considered as optional for anyone who would be faithful to the teaching and witness of Jesus Christ.

It has never been possible for Christian belief to remain a purely private, individualistic matter. From the very beginning and with roots going back to the prophets of ancient Israel, Christianity has always been close to critical conflict with the society in which it exists, championing the cause of the poor against the rich, the weak against the strong, the outcast against the socially successful. (Campbell)

To champion such a cause is to champion the cause of liberation of PWDs, towards their full inclusion and participation in all facets of life.

As the WCC Interim Statement concludes, in our attitudes and actions towards one another, at all times, the guiding principle must be the conviction that we are incomplete; we are less than whole, without the gifts and talents of all people. We are not a full community without one another. The church has no option in responding to and fully including PWDs. It is its defining characteristic.

Disability, Society, and Theology

CHAPTER TWO

Claiming and Developing a Disability Hermeneutics: Towards a Liberating Theology of Disability

Arne Fritzson

What is Hermeneutics?

Hermeneutics in Swedish is a difficult word with different meanings in different contexts. It can mean a certain way of doing research – when applied to the fields of society and human behaviour. It can also simply mean – the understanding of interpretation theories. In this Chapter, we shall define hermeneutics in a more qualified way as a certain type of philosophy. This philosophy draws on the thinking of Friedrich Nietzsche, Martin Heidegger among others.

In this kind of philosophy, *interpretation* is the key concept. Interpretation, according to this philosophy is the only means we should use to understand our world. It further states that, we cannot understand things and concepts as they are in themselves, without interpreting them. Also, our understanding is part of our own personalities. It is influenced by our own personal experiences. How we understand certain concepts is a combination of what we know from experience and our individual perceptions.

That means that each interpreter has his or her own unique understanding of the meaning of what he or she is interpreting. There

is no one accepted understanding of the concept from which all the other interpretations are derived. Instead, there are several meanings and interpretations.

That does not mean that this kind of philosophy is totally relative, and regards any interpretation as good as the other. There kind of deliberations, it is not a question of right or wrong. Some people believe that our interpretations are always not equal to the reality we try to depict. In a way, every interpretation is wrong because every individual interpreter is partial. From a theological perspective we can say that it is only God who understands reality as it actually is. We imperfect human beings can only interpret reality from our own narrow perspectives.

This means that *plurality* is a central concept in this philosophy. Since there is no correct interpretation, there is need to respect other interpreters and their interpretations. However, we should not discourage conflict on interpretation but welcome them as healthy and constructive. Furthermore, the tensions brought about by conflicting interpretations will open up new possibilities of reaching a deeper meaning and understanding.

This kind of philosophy is in particular interesting to theologians who are looking for a Christian theology about disability. Disability is a peculiar concept. It encompasses dissimilar conditions for people who are also diverse. For example, it is quite different not to be able to see, hear or walk. A person who cannot see needs quite different adjustments in his or her environment compared to a person who is not able to walk or hear. Despite this unlikeness, we call all of them “persons with disabilities”, which implies that they have something in common. Is that not quite a weird idea?

In my opinion, the concept of disability as viewed by society is basically a political idea. We can trace its roots to the poor laws that were adopted in European countries in the 17th Century. These laws specified who was to be described as poor. In this case, the laws referred to those who could not afford basic needs. The main source of limitations of the ‘poor’ rested in their ‘bodily constitution’.

These laws and the political decision created the first category or entity of people ‘united’ yet they had so unlike conditions. This is the category we now know as people with disabilities.

This clearly shows that there is no exact representation for understanding the concept of ‘disabilities’. Every perception is basically a description of a category of people that in its roots is profoundly ambiguous as discussed above. To a great extent, those who attempt to interpret disability only make a distinction between those who are seen as ‘persons with disabilities’ and those who are ‘able bodied’. We can as well refer to them as temporarily able bodied (TABs), since some acquire disability after birth but also since everyone potentially can acquire disability at some point in life.

This kind of distinction raises new problems. First, there is not one interpretation that is right everywhere and all the time. Every interpretation has the potential to be offensive in certain contexts. This makes a hermeneutic approach particularly valuable when it comes to the issue of explaining disabilities. In this approach, there is sensitivity to the ambiguity for different types of disabilities, conditions and awareness that we need different ways to interpret reality in order to grasp different nuances in the human life. Different interpretations that are in conflict with each other can stand together and challenge or complement each other. This can help us to see that reality is always larger and more complicated than our own interpretations of it.

The concept of *kenosis* makes it even more important to develop a Christian theology of disability. Kenosis is a Greek word that is loosely translated in English as *emptied*. The word is used in Philippians 2:7 and is of special importance in our understanding of Christian faith. According to Paul, the word describes Christian attitude to: “have this mind among yourselves, which is yours in Christ Jesus” (Phil.2:5). It also summarises the meaning of Christology for Christian faith. Jesus says that he goes to prepare a place for his followers (John 14:2).

That means that Jesus did not count equality with God but *emptied* himself in order that we could be saved by God and receive forgiveness for our sins and gain eternal life. Jesus' atonement can be interpreted as an act of God's hospitality and generosity. God refrained from a space that rightly was His in order to give it to us. In this reading, salvation means that God provides a space for us by denying Himself.

Kenosis has become an important concept for hermeneutic philosophy because it shows a hermeneutic attitude towards plurality of interpretation. The interpreter has to decide which form his or her interpretations should have. That choice shows the mind of the interpreter. If the interpreter has the mind of Jesus Christ, the interpretation will show the attitude of kenosis. The interpretation should not have a form that demands that other interpreters should do the same interpretations. Instead, the interpretation will have forms that allow other conflicting interpretations. In choosing kenotic forms for interpretation, the interpreter shows the mind of Jesus Christ, his hospitality and generosity.

The idea of interpretation with forms that are kenotic is particularly helpful when it comes to forming a Christian theology of disability. It gives us tools to handle the ambiguities that are a part of every discourse on disability. It helps us to see that there is not one interpretation on disability that is the right. Instead, we begin to see that every interpretation has its advantages and disadvantages. We need different interpretations to get more comprehensive understanding of disability.

On this issue, many churches look for "quick fix" solutions in order to understand disability. They desire a document with clear and distinct instructions on how they can make the church accessible for persons with different kinds of disabilities. Underneath such a wish is the thought that the issue of accessibility for persons with disabilities is quite easy. As long as you have good instructions, they reason, the rest is easy.

Sadly, the problem is much deeper and harder to solve. The experience of life with disabilities challenge our very understanding

of what a human life is, what is healthy and what is unhealthy, what is a good human life and what is not. For the church to become fully inclusive and accept people with disabilities, it needs to grapple with such issues. Otherwise it will not be able to let people with disabilities to be members of the church on their own conditions. Instead, PWDs will always be members on the conditions of the 'able bodied'.

In that case, PWDs will always be exceptions to which the church has to adapt; they will always pose problems that the church has to solve.

In 1 Corinthians 12, Paul says that when the congregation comes together, everyone has a contribution. In order to experience this blessing, the church needs to challenge its own understanding of what it is to be a human being. That is called theological anthropology. We must understand that experiences of disabilities are not exceptional that special human beings have but are part of the collective human experience of what it means to be human in God's world. In order to do that, the church needs to develop a hermeneutic that is sensible to these experiences. Only after such a move can the church become a fully inclusive community for all God's people.

Disability, Society, and Theology

CHAPTER THREE

Perfect God and Imperfect Creation: In the Image of God and Disabled

Joseph D. Galgalo

Introduction

John was a happy child. He grew up in a relatively well-to-do family. He was the top student in the Kenya Certificate of Secondary Education (KCSE) national examinations in his district. This secured him a rare scholarship to do medicine at a prestigious university. While in his second semester at the university, he was involved in a car accident and sustained multiple fractures. His right leg was completely crushed that the doctors had to amputate it. He also lost effective use of his right arm. It took John a while before he came to terms with his loss and accepted his new condition. He soon came to realise that disability did not only impose bodily limitations – he also faced new cultural, social and personal dynamics. These cultural and social realities that he faced redefined his very identity.

Just when John thought his new self-identity was no longer a problem to him, he suffered a severe stroke. While addressing a group of people with varied disabilities, John narrates his experience in the following words:

In addition to my physical diminishment, the stroke changed my understanding of self. I feel my true identity is lost and what is left of me is a pale shadow of who I used to be. I can't help feeling that

whatever is left of me is barely recognisable and now helplessly trapped in this shell of a body (Verbal communication)

A listener in the audience asked, “I wonder what you mean by ‘the loss of your true identity.’ Aren’t you like everybody else despite your disability?” Aren’t we all made in the ‘image of God’ – our true selves?

This Chapter discusses the meaning of ‘human beings’ as beings made ‘in the image and likeness of God’. It also raises the question of the existence of ‘imperfections’ in a world created and sustained by a perfect God. Perhaps we could begin by asking, “What does it mean to be ‘in the image of God?’ How can we describe ‘the image of God?’”

The Image and Likeness of God: Traditional Interpretations Reconsidered

The Christian doctrine of creation accords human beings a special status and place in the whole of the universe. Human beings are affirmed as uniquely created in the image and likeness of God. The idea is based on Gen 1:26-27, which says, “God created man in his own image, in the image of God he created him (Hebrew, *b’tzelem elohim*).” The meaning of the phrase ‘the image and likeness of God’ (v.26) down the centuries has generated many different interpretations. The image and/or likeness of God in us has been seen in terms of physical, cognitive, spiritual, relational or functional elements that constitute what it means to be human. Let us examine a few of these interpretations.

The Image of God: A Substantive Interpretation

The Early Church Fathers show keen interest in the meaning of image and/or likeness of God as relates to human beings. Irenaeus may be the best place to begin. In his short writing, *The Demonstrations*, Irenaeus explains that the “image” and “likeness” constitutes two different things. The likeness, he argues, refers specifically to God’s creation act of ‘breathing into Adam’ after

making him. He further argues that God endowed Adam with divine ‘likeness’ consisting of reason and freedom. Since “reason” and “freedom” are part of divine attributes, he is of the opinion that human beings are special creatures by virtue of sharing something of a divine nature. This means that cognition and the ability to exercise freewill are basic to what it means to be human.

Irenaeus further contends that while the image specifically refers to the act of ‘formation,’ ‘likeness’ on the other hand, specifically refers to the act of ‘inspiration.’ By breathing into him, God gave Adam a spiritual or divine endowment, after God’s own likeness. The likeness was then lost as result of the Fall. It was, in the first place only seminal in nature and Adam was meant to grow into spiritual maturity and attain the fullness of Godlikeness. When the likeness was lost, the image remained but only in a residual form. Irenaeus’ substantive interpretation of the image and likeness is perhaps best summarised in *The Demonstrations*, where he writes:

God fashioned man with his own hands, taking the purest, the finest and the most delicate elements of the earth, mixing with the earth, in due measure, his own power and because he sketched upon his handiwork his own form – in order what would be seen should be godlike for man was placed upon the earth fashioned in the image of God (*eikon*) – and that he might be alive, He breathed into his face a breath of life: so that both according to his inspiration and according to the formation, man was like God.¹

In summary, this teaching holds that, the likeness of God in which the human person was made, refers to some supernatural attribute with which Adam was endowed although in a limited measure. It is about the gift of original righteousness that enabled the human person to know and honour God.

¹1:11, see Translation and Introduction to ‘*On the Apostolic Preaching*,’ by John Behr, (NY: St. Vladimir’s Seminary Press Crestwood, 1997), 46-47

Although this view remained dominant down the centuries right through the Medieval times, it is problematic in two ways. First, its interpretation of the image is too materialistic. Second, the claim of total loss of likeness fails to recognise the spiritual nature of humanity. We always share something of God's substance, even when we totally reject God, and live in 'self-denial' (the image of God) as it were. Therefore, the distinction is totally uncalled for.

Like Irenaeus, Augustine states that 'likeness' refers to the spiritual gift with which God endowed humanity (*donum superaditum*). This primarily refers to moral attributes such as righteousness or holiness, with which humanity was originally endowed but was lost as a result of the Fall. The image, dented but never completely lost after the Fall, is the essential element that constitutes what it means to be human. It is the irreducible minimum without which one cannot be said to be human. This implies that everyone, recognisable as a human being is without exception made in the image of God. The image, in this logic, is that which makes human beings distinct and different from the rest of creation. We say, 'this is a person and not a dog or a horse,' not just because of form or appearance but because of the image of God that is basic to human identity, the *real* true self or 'humanness'. The issue here is having the spiritual capacity to comprehend God, and in so doing seeing one's true self or identity. This interpretation essentially places the image in the spiritual dimension of personhood, the soul, rather than the body. Saint Augustine in a passage in the *De Trinitate* expresses this dimension in the following words:

"The image of the creator is to be found in the rational or intellectual soul of man, being implanted in the soul's immortality ... the soul of man cannot but be rational and intellectual ... it has been created according to God's image in respect that it is able to employ reason and intellect and apprehend God and behold him ... though this image may be so dimmed as almost to cease to be, though may be obscure and distorted ... it never utterly disappears."²

²*De Trinitate* 14:6

Augustine also points out one cardinal truth: that ‘being in the image’ of God does not primarily refer to the bodily ability or a certain form of able ‘*body-ness*’ with regard to the physical or cognitive nature of a person. In this regard, Augustine’s interpretation, his distinction between the image and likeness aside, is helpful. The image is essentially connected with the soul, which uniquely shares the attribute of immortality with the divine. The image is that which is of God and like God – is immortal, and being basic to every person, whether able-bodied or disabled. The image can be maximised or minimised. It can also be diminished but cannot be destroyed completely. Fall from righteousness or loss of holiness should be regarded as the primary cause of the diminutive nature of the image, which unlike the physical or *material* disability is associated with creaturely imperfection as opposed to God who alone is perfect³. In this sense, the image primarily has to do with the human response to God, a response which may take various forms and is ever present even when one consciously rejects God.

Relational View of the Image of God

Most Reformers reject interpretations that distinguish between the image and likeness. Martin Luther points out that Gen 1:26 does not support such interpretation.⁴ The verse should be interpreted in the light of Hebrew speech that typically employs parallelisms and wordplay. Luther’s observation is pertinent. Gen 1:26 uses both image and likeness but Gen 1:27 has image only. In Gen 5:3 both words are used but only likeness occurs earlier in Gen 5:1. Image alone is used in Gen 9:6 to bring out the meaning expressed by both. The

³By ‘material disability’ I mean all human disabilities such as cognitive/ learning (cp. Dyslexic, etc); auditory; visual; motor/physical paraplegic); speech/language, etc. The word material will appear in italics in this text whenever it is used in this sense.

⁴Martin Luther, “Lectures on Genesis,” in *Luther’s Works*, ed. Pelikan, Jaroslav translated by Schick, George V (St. Louis: Concordia, 1958), vol. 1, 60-71

New Testament references (cp. 1 Cor. 11:7; Col. 3:10; Jas 3:9) use only one or the other of the two words. Based on these references, it is plausible that the words ‘image’ and ‘likeness’ are used interchangeably.

Martin Luther holds that the image refers to the human beings’ rational and moral nature. The image was affected after the Fall but persisted in form of a residue or fragment of what it originally was. The residue has the potential to gain full restoration by means of God’s grace. As Gen 9:6 shows: “whoever sheds the blood of man, by man shall his blood be shed; for in the image of God, has God made man” God intends and wills to let the human being continue to be in the image of God, even after the Fall. Luther’s assertion helps us to make one important observation. That, *all* as are able to respond to God’s grace are in the image of God, since the image is located in the human spiritual nature and is not about physical form.

According to John Calvin:

The integrity with which Adam was endued when his intellect was clear, his affections subordinated to reason, all his senses duly regulated, and when he truly ascribed all his excellence to the admirable gifts of his maker. And though the primary seat of the divine image was in the mind and heart, or in the soul and its powers, there was no part even of the body in which some rays of glory did not shine.⁵

Calvin’s thesis supports our earlier intimation that the image is to do with the human being’s spiritual nature. It is about spiritual capacity – potential or actual, that seeks and responds to God. It encompasses the ability to recognise God as the supreme spiritual being all not notwithstanding.

There is another interpretation called the relational view of the image. Emil Brunner, the proponent asserts that the meaning of the image can only be truly known if we first comprehend God’s act of

⁵*Institutes* I. 15:3

self-disclosure. This is possible to receive through hearing the word of God. She further argues that the word of God constitutes and conveys the image of God. Engaging with the word at both epistemological and ontological level leads to the recognition that the image of God is the essential human self. Brunner distinguishes two aspects of the image; the ‘ideal’ and the ‘actual’. In the words of Millard Erickson, Brunner describes the ‘ideal’ – also called the ‘formal’ aspect of the image as: “the *humanum* that which makes a person human, distinguishing the human from the animal, as a rational being, responsible and free.”⁶

The aspect of the image that Brunner calls actual or material was lost after the Fall. The ideal aspect of the image which makes human beings distinct and different from the rest of creation survived. In any case, humanity never lost the potential to recover the material or the actual nature of the image which was lost. It is potentially available to all who receive God’s revelation and respond to God’s word and enter into relationship with God. The capacity to relate is what essentially makes a person human, that is, a being in the image of God. A human person who is out of relationship with God loses the actual image of God but in as far as the ideal aspect of the image is concerned, a person is always in the image of God. When a person responds to God and enters into relationship with Him, the actual image is restored. However, it has to be sustained in a continuous, meaningful or fruitful relationship, which acts as a mirror in reflecting the identity of a person as one in the image of God. The relational view overlooks the fact that one is always in the image of God, and therefore human, even when the person is not in any active or actual relationship with God or other humans. We uphold that image is basic to who we are, regardless of the quality of our relationships.

⁶Erickson, Millard *Christian Theology*, 2nd edition, GR, Michigan: Baker Academic, 1998), p.524 cp. Emil Brunner, *The Christian Doctrine of Creation and Redemption* (London: Lutterworth, 1952), 55-57; *Man in Revolt* (Philadelphia: Westminster, 1947), 64ff; 103ff

Karl Barth agrees with Brunner that the image of God in human beings means God's intention and eternal will for what humanity should be. God wants us to be in relationship with Him and His creation.⁷ To be or to exist means to be or to exist in a relationship with God. Analogically, the true meaning of being is reflected in the being of God Himself who exists in a perfect harmony of the relationships between the persons that form the Trinity. Therefore to be in the image of God means to have the capacity (or at least the potential) to exercise 'I-thou' relationship with God at one level and the rest of God's creation at the other level. I-thou relationship constitutes what it means to be human – one is human because of 'thou' with whom 'I' relates and finds meaning of existence or the reason 'to be'.

It is true that the reality of what it is to be human is made clear in divine-human encounter or revelation. This is especially so in the encounter with Jesus Christ in whom God is revealed in a very special way. Jesus' humanity and his exemplary life – a life He lived and died for others reveals what the true image of God is really like. The image itself, however, is not simply about epistemological disposition or ability. It is that which makes a person essentially a person, even when he or she has fallen out of relationship with God. This is so, especially because, the image is about the spiritual nature of being, and on this basis alone always bears affinity with God.

Functional Interpretation of the Image

The relational interpretation does not tell us much about the meaning of the image of God. It only states that the image is that which is experienced when one encounters God and enters into relationship with him. Another view interprets the image in a functional sense. Humanity is endowed with the capacity or potential to perform certain functions. At the time of creation, Adam was given a representational

⁷Karl Barth, *Church Dogmatics* (Edinburg, T&T Clark, 1958), vol.3 part I, 184ff; 196ff

role as God's viceroy. God gave human beings the responsibility and sovereignty to govern. They were to have authority over the rest of creation. Gen 1:26-27 implies that God endowed the human beings with divine image and likeness in a functional sense. Therefore, they were to discharge this representational function and responsibility. Gen 1:26 is often cited to support this interpretation as follows – "then God said, 'Let us make man in our image, after our likeness; and let them have dominion over the fish of the sea, and over the birds of the air, and over the cattle, and over all the earth, and over every creeping thing that creeps upon the earth.'" Ps 8:5-6 also links God's purpose for creating humans with human functional roles lending further support to the functionalist view of the interpretation of the image of God in human beings. Based on these references, we can conclude that human beings are in the image and likeness of God on account of their similarity with God in a functional sense.

The mainstay of this view is that humanity is the apex of God's creation. God placed humanity on earth and uniquely endowed them with the ability to exercise sovereignty. Humanity, therefore, is like God – responsible for the whole of creation. This view supports a host of other doctrines including human privilege, stewardship of God's environment, and alignment of the human will with the will of God, among other things. However, Gen 1:26, does not necessary link function and image; the verse spells out both the essential nature of humanity and at the same time the role God was to assign to man. The two are totally separate.

Also, if the functional view or the representational role is taken simply to mean the perfunctory role, it might give an impression of a material view of the image. This is not acceptable because it sets a boundary between able and disabled persons by defining people according to their limitations rather than their abilities and potential. An interpretation of the 'image' that defines some human beings as 'outsiders' and others 'insiders' is too materialistic and problematic. It negates the vision of a common humanity created in the image of

God without exception. It is in this light, that we propose a spiritual view of the image.

Towards a Spiritual Interpretation of the Image

The Biblical perspective about the ‘image’ is rather limited. The meaning of the ‘image of God’ however, is clear in one sense. It refers to the most basic or essential nature that constitutes a person, without which one cannot be recognised and classified as a human being. The cognitive and volitive faculties, which set humanity apart from the rest of creation is part of what it means to be in the image of God. This, however, should not be understood as referring to the *material* ability or the nature of functional abilities of such faculties. It should rather be understood as referring to the potential of these faculties and the essential spiritual characteristics of the human soul. The image is the basic human constitution that characteristically searches for fulfilment, the ultimate meaning, and that which is of ultimate salvific significance. There is inevitable connection, in this sense, between the human soul and God – that is, if God is accepted as that ultimate good and source of all meaning. This connection between God and humanity is the human true self-identity. It can be described in two ways. First, ‘the image’ is that which humanity shares in common with God as well as the human inclination that always searches for God (whether this is consciously acknowledged or not). The second is the spiritual nature with which God endowed humanity in the first place and called it his image. Thus, we can conclude that a human being’s true identity is found only in and with God.

We also need to take note of the pastoral significance of the doctrine of humanity as a creature uniquely created in the image of God. True humanness transcends bodily (*material*) or cognitive faculties. It embraces a spiritual dimension, which is the true human self – the image of God. This means that all humanity by virtue of spiritual endowment which is essential to their nature, are made in the image of God. This is true – human ‘fall’, imperfections, and even the capacity and freedom to reject God notwithstanding. The

human irreducible self, the non-*material* or the inner spiritual self is what we call the ‘image of God.’ The logical sequel to this argument is that every human being by reason of being in the image of God has the right to be and enjoy full dignity and respect deserving of that image. Therefore, all must be treated equally and justly in this regard. To deny any human person the right to be and the freedom to pursue life in all its fullness is to deny the image of God and to contradict what God intends humanity to become. In ethical terms, this means sanctity of life, fair and just society, equal opportunities for all, and the freedom to pursue individual God given talents.

If one is made in God’s image – the journey into God through the spiritual act of worship (not just outward physical form of performing liturgy) is a journey into self-discovery. It involves the actualisation of the real or true self as one who truly is the image of God. Realising true self-identity is therefore first and foremost to be found in worship. *Material* disability may present a whole range of cultural and social challenges, and a sense of physical diminishment as stated elsewhere. But, it does not in any way diminish true self, that is, the image of God. This leaves us with one question: How can we lay claim to our true self; the image of God, and yet our diminishment, fallen nature and human imperfections make us so different from the perfect God in whose image we claim to be?

Able God and the Disabled Body

The biblical image of God is so wrapped in the Hebraic worldview that is confined to a narrow description of what is normal or perfect. As John M Hull observes:

The Bible is almost unequivocal in expressing the point of view of the able world. God is portrayed as an able-bodied God. God has powers of sight beyond the normal, powers of knowledge beyond the average. God is super-abled. It is inconceivable that God should be a disabled God. ‘Surely the arm of the Lord is not too short to save, nor God’s ear too dull to hear’ (Is 59:1). The result is a humanity of convergence, where the signs of redemption are to be found in the recall of the peripheries to the centre. ‘Then will the lame leap like the

deer, and the mute tongue shout for joy' (Is 35:6). This convergent humanisation is modelled upon the perfection of the creation, in which everything reproduces according to its kind (Gen 1:24f) so assuring the stability and the continuation of the characteristics of normality. The convergence is rooted in the domination of the majority and returns in eschatological visions toward the singularity of the average.⁸

The background to this dominant biblical view of the world is the narrow, almost too materialistic understanding of the image of God. Incarnation on the contrary, challenges this narrow view of what the image would 'normally' mean. Jesus does not only challenge this narrow view but also fully shares the experience of having been disabled. Jesus was blindfolded and experienced what it means to be without sight (Mk 14:65, Lk 22:64). He was tortured and denied the use of his limbs (Mk 15:24). He was also despised and pushed to the periphery (Gal 3:13, Heb 13:12). The resurrected Christ bears scars and marks of disability. As incarnate God, Jesus presents the image of a disabled God (Luke 24:36-39). A powerfully illustrated ministry of Jesus is not in his healing of broken bodies and restoring sanity to the possessed but more so in his embrace of disability. As Isaiah prophesied, Jesus:

Grew up like a young plant, and like a root out of dry ground. He had no form or majesty that we should look at him, nothing in his appearance that we should desire him. He was despised and rejected by others, a man of suffering, and acquainted with infirmity. Like one from whom others hide their faces he was despised, and we held him of no account. ... we accounted him stricken, smitten by God, and afflicted (Is 53:3-4).

⁸John M Hull, "A Spirituality of Disability: The Christian Heritage as both Problem and Potential," in *Studies in Christian Ethics*, vol.16 no. 2, 2003, 21-35

Isaiah powerfully demonstrates how our social concepts of perfection, inferiority, superiority, functionality and our sense of value in turn inform and shape our warped theological views about the ‘disabled’ and the ‘normal’. We are not perfect because we are in the image of the perfect God; we are in the image of God, because God created us so and shared our brokenness that we may share in his perfection.

The brokenness of God, which takes our attention away from the ‘perfectibility’ of God, helpfully throws such a fresh light on our perspective of normalcy and perfection. We begin to see afresh the meaning of the image through not our cultural lenses of the hegemony of the able-world but through a ‘disabled God’ who does not confront us with power and authority as the world expects, but a God who invites us with bleeding broken arms stretched out on a cross. It is in light of this that our perception of perfection transcends ‘the human normal’ and embraces the true knowledge of the image. The image of the wounded God illustrates that even though the body may be wounded, the image never loses a given wholeness – the wholeness of the divine in whose image the human being is made. The image of one out of relationship with God ‘may be so dimmed as almost to cease to be,’ as Augustine⁹ observes, but is never completely destroyed. We are spiritual beings and as such, and on that basis, *the very image of God*.

There is much in the biblical tradition that has led us to believe that ‘being in the image of God,’ conforms to a certain standard of perfection with regard to both moral (or spiritual) and bodily sense. Often being ‘normal’ or the concept of wholeness is uncritically linked with the concept of righteousness, a benefaction or a special favour from God. This explains the connection often made between the forgiveness of sins and the experience of individual healing in many churches today. As Nancy L. Eiesland rightly says, “This has led to the practice of the church viewing people with disabilities as

⁹*De Trinitate*, ibid

objects of curing or ministry and not as companions on the journey.”¹⁰ The background to this theology, I would add, arises from our faulty concept of the image of God in human beings. We should never lose sight of the fact that God is spirit and to be in his image has very little to do with our bodily existence or corporeal nature.

It is our anthropomorphic language about God that often leads to inappropriate conception of God. God is not of ‘material/physical nature’. Our mental images of a physical God are a creation of God in our own image, an image of what we would like to become. God is spirit, and in true spirit alone we can comprehend his image, and find our true self; for that true self is the image of God who is spirit. As Dolphin observes:

God is a spirit and not a material being – we do not look like God physically. The image of our Creator which we all bear is primarily an invisible, inner likeness. In regard to attributes of personality, mind, creativity, capacity for love and express emotions, the existence of will, conscience, imagination, memory and moral responsibility, and capacity for worship – God has made us very much like Himself.¹¹

It is important that we distinguish between ‘who we are’ and ‘what we have’. The physical body is ‘what we have’ and not ‘who we are’. Intellectual and physical abilities are also ‘what we may have’ but not ‘who we are’. Above all else, it is as spiritual beings that we are *the very image of God*.

Conclusion: Perfectibility or Moral Integrity?

God alone is perfect. However, creation inevitably lacks absolute perfection. In a creation where perfection is the final goal of the

¹⁰*The Disabled God: Towards a Liberatory Theology of Disability* (Abingdon: The Christian Century Foundation, 1997), see http://findarticles.com/p/articles/mi_m1058/is_n27_v114/ai

¹¹Lambert Dolphin, *Made in the Image of God* <http://ldolphin.org/Image.html> retrieved June 14, 2008.

process of becoming, imperfections, inabilities, limitations, deformities and other forms of infirmities are potential and actual possibilities within the created order. Humans, although created in the image of God, lack absolute perfection as found only in God. The created order is necessarily at a distance from the absolute perfection, and consequently suffers limitations due to the lack of fullness as a result of being different and 'less than God'. The difference also means a necessarily contingent nature of creation. If God is God, and human beings human beings, the world has to be the way it is, for contingent nature cannot be otherwise. If the world were self-sufficient, it would be a god to itself. Limitations would have no place in it. But now that the world is contingent, then, such a world cannot be perfect without being a contradiction to itself. The relevance of God, and the logic of difference between a self-existent, self-sufficient being on one hand, and the finite, contingent creatures on the other, makes sense of the creaturely limitations. Such is the mark of being less than divine. Every human being, on account of being in the image of God, has the potential to cross the divine-human divide and gain immortality or perfection (called eternal life in the Christian traditional language). At our *material* level or bodily existence, this calls for moral integrity to embrace humanity inclusively. Our approach must transcend our views of human perfection and social constructions that are narrowly tied to able-bodied or cognitive endowments, and other categories so often erroneously applied in interpreting the 'image of God' in which the human person is made.

Disability, Society, and Theology

CHAPTER FOUR

Sin, Suffering, and Disability in God's World

A. Wati Longchar

Introduction

There is no theology that is timeless and unchanging. Theological reflection is an ongoing process. Though disability movements around the world have created much awareness on the right of persons with disabilities (PWDs), we still have a rather negative theology towards them. It seems like Christian theology is a reflection on faith primarily by able-bodied people for the able bodied. Theological reflection from the perspective of PWDs is still absent in the Christian tradition.

PWDs whose voices are never heard in church, those whose experiences are never considered in doing theology, are raising new theological questions. They are asking: Are we not created in the image of God? Are our disabilities a curse from God? Are our physical impairments a result of our parents' sins or our personal sins? Are we sinners? Why are we excluded from the church? Why do people look down upon us as if we are inferior beings? How do we contribute our gifts in the church and to society at large? Without addressing these issues and concerns, Christian theology will always remain incomplete. These misgivings demand a new way of reading and doing theology.

Superstitions

I come from an ethnic background in India where many superstitions exist, just like in many African communities. In our community, we believe that bad things or unfortunate events are caused by the evil spirit. For example, people consider afflictions that result from accidents, disability, death or even poor harvest as a consequence of bad action by the person affected. A few plausible examples of bad actions are:

- killing an animal when one's wife is pregnant
- giving false witness in a land dispute
- killing an innocent person
- telling lies
- violation of religious observance
- violation of a restricted days
- taboos

The above are seen as works of evil. Some of the consequences or afflictions directly linked to bad action are:

- blindness
- cripple
- still born
- mental imbalance
- demon's possess

So, PWDs in my community are considered as a result of punishment. If such person is given his or her rightful place in society, the whole village where he belongs will be punished. Therefore, PWDs are not given a chance to be what they want to be. For example, to this day, PWDs are not allowed to sit in village councils or be involved in religious matters.

In some circumstances, PWDs are not allowed to speak in public. This custom still dominates ethnic thinking. In this case, it appears like ethnic tradition has colluded with the scripture. The result is, PWDs live in very poor conditions, suffer many forms of discrimination and are isolation in society.

Sin and Suffering “Outside” the Structure of God's Creation

Creation is an expression of the purpose and grace of God. The world and all that is in it, including human life, are gifts of God. They are also dependent on God. Taking the Greek philosophy of order in creation, Christian thinkers in history have expounded the order of creation within the hierarchical framework where people with disabilities are treated as ‘outsiders’. They have no personhood and reflect the imperfect creation of God.

Thomas Aquinas’ has had the greatest impact in the life of the church and continues to influence it to this day. For instance his views on the order of creation. Aquinas argues that God, in the beginning, created a hierarchy of creatures in the order of their degree of perfection simultaneously.¹ Angels were created as pure spiritual beings, and are at the peak in the hierarchical order. Since they are above human beings, they are perceived as holier and closer to God.

Among the other creatures, humans place next to angels. Since they are rational beings, they are given the ultimate control over all creation. This hierarchical order is a divine design. It is apparent that “imperfect beings are to be used by the perfect beings”². Aquinas further explains that material creatures, like all others, were created that they “might be assimilated to the divine goodness”³ through rational creatures. The creatures lower than the “spiritual

¹D. M. Chenu, *Towards Understanding St. Thomas*, trans. A.M. Landry and D. Huglus (Chicago: Henry Regnery, 1964), pp. 301 ff. also Etienne Gilson, *The Christian Philosophy of St. Thomas Aquinas*, trans. L.K. Shook (New York: Random House, 1956).

²Thomas Aquinas, *Summa Theologia*, ed. by the English Dominican Fathers (Burns, Pates and Washbourne, Ltd., 1922), Part I, QQ LXXV-CII, 327.

³Thomas Aquinas, *Summa Contra Centiles*, ed. by the English Dominican Fathers, (Burns, Pates and Washbourne, Ltd., 1922), Part II, Ch. CXII, 58.

human creature in the hierarchy”, are simply assimilated in the divine goodness “by serving the human creature.”⁴

Since the intellectual nature which represents the image of God is superior to material nature, the whole material nature is subordinate to intellectual nature. In other words, the whole material nature exists for humans’ use because humanity alone possesses rationality and exercises freedom. This quality is considered as ‘the image of God’.

Therefore, in Aquinas’ structure of creation, there is no room for persons born with impairments. More particularly, there is no room for persons who lack the capacity to reason because they lack ability to govern the lower creatures. By inference, it would mean any form of disability makes one less than human – in other words not created in the image of God. This hierarchical order excludes PWDs and treats them like ‘outsiders’. One might think they are simply imperfect beings without any worth and value. Their disabilities are ‘a manifestation of sin’ and they are predestined to suffer pain. It is within this theological framework that many theologians propagate the concept of ‘the image of God’, ‘sin’ and ‘wholeness’.

Sin and Disability

An important biblical insight that has influenced the church in particular and society in general is the doctrine of sin and creation of humanity. The position of persons with physical impairment in society created much debate in the Christian church. The main theme rotated around the question of perfect God, imperfect creation and the consequences of sin. Two positions of the church may be cited here to show the interconnection between disability and sin.

Disability as Consequence of Sin: A Source of Exclusion

The concept of sin is interpreted differently in Christian circles. Some theologians describe it as ‘missing the mark’, while others

⁴*Ibid.* 59.

speak of 'dethroning God and enthroning oneself at the centre of one's life'. But the most crucial issue is: how does the Christian understanding of sin affect the lives of PWDs?

A dominant view about physical impairment is that it is the consequence of sin. Even today majority of Christians would say that it is the consequence of sin, punishment from God or a curse to the family. This belief is further re-imposed by the doctrine of rebirth (*karma samsara*) in Hinduism⁵ and primal religious belief in evil spirits⁶. This wrong interpretation of disability by linking it with sin has caused much damage to PWDs who live healthy lives. It has become a source of exclusion in society.

Classical theologians regarded the "original sin" as the universal and hereditary sinfulness of man since his fall. It is accepted that since all human beings are the descendants of Adam and Eve, they all inherited the sin of their parents and then became sinners. Augustine taught that the original sin was transmitted through a sexual act.⁷ The original sin has distorted God's perfect order of creation and the consequence of which is imperfect order of creation. Since imperfect creation is the result of sin, PWDs do not come under the scheme of God's grace. Many wrongly believe that disability is a direct consequence of sin and the work of demons, that it is a curse and punishment from God. Though the offences PWDs commit are relatively insignificant, many people still think that disability is a manifestation of parental sin. Most PWDs are not even conscious of their so-called misdeeds. Unfortunately, the church condemns acts like smoking, drinking, or watching secular movies more than sinful acts like discrimination, prejudice and

⁵The doctrine of rebirth teaches that the cyclic process of life. The condition of present life is determined by the past deeds. Disability is product of past misdeeds and we can do nothing for it.

⁶The traditional primal religion strongly advocates that "bad things are caused by the evil spirits and good things are the result of the blessing of benevolent spirit".

⁷Elizabeth Clark, *Women in the Early church, Message of the Church Fathers*. Liturgical Press: Collegeville, Minnesota. 1983.

exclusion that the society metes out on PWDs. The latter has serious consequences in their lives.

There is sufficient proof that Christian theology of (the original) sin is the root of the denial and exclusion of PWDs in society and church. It gives justification to escape from institutionalised form of social evil. The belief that impairment is caused by demons or is a consequence of sin has deprived PWDs a chance in church and public life. This wrong notion has not only contributed to the neglect of a people's real life situation, but has also affirmed targeted oppressive tendencies. It has not given direction for the transformation of the lives of PWDs. This wrong understanding has contributed to exclusion of PWDs from active involvement in spiritual, social and developmental life of the church.

Sin and Image of God

In order of creation, the imperfect beings have no space. It might as well be said that they are not worth of protecting. Throughout the centuries, the churches have never acknowledged that PWDs are created in the image of God. Some theologians exclude them by interpreting 'the image of God' in terms of 'perfection'. Perfection was understood in terms of physical and mental endowment. Some say there is no beauty in the disabled. Any form of disability, they argue, makes a person less than human. Some understood in terms of 'rationality'. Persons who are not articulate do not represent God's image. Some interpretations focus on the exercise of power. God created humans to exercise power and have dominion over the rest of creation, a capacity into which God invites humans to participate. The others interpreted in the 'image' relation to human capacity for creativity and freedom. Since PWDs cannot exercise creativity and freedom fully, they cannot be counted as full 'beings'⁸.

⁸Gordon Cowans, "Towards a Liberatory Theology of Disability; Humanity in Creation, Disability and the Image of God" in *Disabled God Amidst Broken People: Doing Theology from Disability Perspective*, ed. by Wati Longchar and Gordon Cowans, (Manila: ATESEA, 2007), 47-48.

These are all abled people's interpretations. They do not respect life especially those who live a healthy life with physical impairments.

Disagreeing with the dominant Christian interpretations, Gordon Cowans, writes:

None of the above formulations takes sufficiently into account the experience of disability, particularly the experiences of persons born with impairments. Many persons are born with impairments which inhibit their capacity to engage and interact with their environment in the same way as others.⁹

The dominant interpretations of sin and the image of God justified extermination of people born with physical impairments. Killing, apart from "imperfect beings" like PWDs, or any person is considered as sin because human life is precious. The reformers who held deliberate discharge of semen as crime were negative towards PWDs. *Onan* deserved to die (Gen. 38:8-10) taught Calvin, for the crime of the unproductive discharge of semen. Deliberate spilling of semen outside of intercourse between a man and a woman was considered a crime worth of death.¹⁰ But in the case of PWDs, Luther and Calvin held them in contempt and justified their removal from society by death as "an act well-pleasing to God". PWDs represent a 'distorted' image of God and so they are sub-human, they taught. A person does not commit crime by killing a disabled person, they further argued.

This lopsided interpretation of God's creation has brought discrimination to PWDs and, denial, exclusion at homes, churches and society. It perpetuates the treatment of PWDs as inferior not only in respect of their specific physical limitations, but also their "total being". They are treated like a second-class people, object-of-charity or even abandoned. Some parents do not give their children

⁹*Ibid.*, 48.

¹⁰Cited by Adrian Thatcher, "The Virus and the Bible-How Living with HIV helps the Church to read it" a paper presented at workshop on "Ethics on HIV & AIDS Prevention" at on 8th January, 2008 at Johannesburg, 5.

who are PWDs adequate food and medical treatment. Some even lock them up with the house or compound and deny them permission to go out. Their presence is considered as a burden, not as a precious gift. Society also makes PWDs absolutely dependent by denying them privileges and opportunities in all areas, including the church. This is sin. It contradicts the Kingdom's value.

Jesus' Attitude Towards Disability and Sin

'Sinners' in the Jewish society were distinguished in two ways: first, there were those who were publicly recognised as criminals. The second category was that of the lowly, i.e. the poor, the blind, the paralysed, the deaf, the lame, the lepers, the crippled on the ground of impurity and sin. They were denied permission to enter the temple or attend festivals. The society avoided them. When they encountered the rich or people of high social class, they did not interact with dignity as equals. They had to keep their low place. They were despised and had no hope.

Luke gives an account of Jesus' attitude towards the so-called sinners and PWDs as follows:

When you give a dinner or a banquet, do not invite your friends or your brothers or your kinsmen or rich neighbours, lest they also invite you in return, and you be repaid. But when you give a feast, invite the poor, the maimed, the lame, the blind, and you will be blessed, because they cannot repay you. You will be repaid at the resurrection of the just (Lk 14:12-14).

Jesus had a message of acceptance, compassion and love. "Jesus intentionally shattered the boundaries created by society and fashioned a new understanding of humanity rooted in the grace of God."¹¹ This was a direct attack on those who discriminated against PWDs in society.

¹¹Albert Nolan, *Jesus Before Christianity* (Maryknoll, New York: Orbis Books, 1976), 167.

Though in the Bible, the causal relationship between sin and impairment is mentioned by Jesus, it is always mentioned in the context of faith and healing. Jesus never associates disability with sin alone. Jesus said, "It was not that this man sin or his parents, but that the works of God might be made manifest in him" (Jn 9:3). Interestingly, PWDs also did not associate their disability with sin. Society and especially, able-bodied people imposed the label 'sinner' on PWDs. PWDs cried out to Jesus not for forgiveness of sins but for healing. One should not confuse 'cure' with 'healing'. 'Cure' refers to bodily, developmental, and psychosocial restoration to what is considered normal. In contrast, 'healing' refers to a sense of well-being that encompasses attitudinal and emotional health¹². A leper asked Jesus to heal his sickness, but did not ask to forgive his sin. That means he did not consider himself a sinner (Mt 8:14). The two blind men asked Jesus for sight, but not to forgive their sins (Mt 9:27-31). They were fully aware that there is no connection between their physical impairment and sin.

Jesus never claimed that he can cure all sicknesses. He never attempted to heal all those who were disabled. Not everyone in Palestine who was sick or disabled was healed by Jesus. Among all the people with physical impairment waiting for the Bethesda to be stirred up, only the man paralysed for 38 years was singled out by Jesus for physical restoration (Jn 5:1-3). Not every person with blindness in Palestine was given sight like the man born blind (Jn 9:1 ff). We should not assume that cure on earth is a must.¹³ Those who say that 'you are not healed because of lack of faith' contradict the teaching of Jesus. This then increases the pain and suffering of PWDs.

¹²Amanda Shao Tan, "Non-Healing, Waiting and Thriving While Living with Disability: Tips from the Gospel According to John" in, *op. cit.*, 88.

¹³*Ibid.*, 88-89.

Jesus also disputed disqualification of PWDs in religious services and public life on the basis of impairment.¹⁴ Physical impairment is neither a curse nor punishment from God. The unclean and sinners are those hypocrites, oppressors and manipulators of law. “Woe to you, teachers of the law and Pharisees you hypocrites!” (Mt 23:13 ff). Jesus rebuked those who thought PWDs were sinners. By accepting them, healing them, protecting them and caring for them, Jesus broke the barrier of separation between the disabled and able people in all aspects of life.

The first followers of Jesus Christ were the disinherited, lepers, blind, sick and low class people from different places in Galilee.

This inclusion of “all people by Jesus in his work are a sign of his special message to restore the human condition to wholeness”.¹⁵ Society should therefore re-affirm that the church is a place where everyone, regardless of individual gift and ability, is genuinely welcomed, given an opportunity to participate meaningfully, and nurtured towards personal fulfilment.

Suffering and Disability

Broadly we may categorise the source of suffering into two: first, the suffering perpetuated by an unjust social system that condones globalisation and patriarchy. Globalisation in my view is a new form of colonialism. The global market has turned human beings, cultural activities and natural resources into commodities for profit. Migrant workers, small scale farmers, consumers, small entrepreneurs and the weak in society are victims of globalisation. The unjust financial system, the ideology of consumerism, materialism, individualism, cut-throat competition and greed have eroded positive living values. The

¹⁴In Jewish society, those with defect in the body were not allowed to come near the Lord’s offering (Lev 21:18-21). The blind and the lame were not allowed to come into the house of the Lord (2 Sam 5:9).

¹⁵Samuel N. Kabue, “Church and Society’s Response to Disability: Historical and Sociological Perspective” in *Disabled God Admits Broken People*, 13.

new value system driven by powerful financial corporations has fragmented society and increased poverty.

Likewise, patriarchy perpetuates injustice to women. Women are denied equal opportunity in religious and public life. This is an institutionalised form of violence. It is demonic. It causes suffering to a large majority of people on the basis of gender. Other sufferings are precipitated by colour, caste, religion and economic status. These are human made sufferings. They are contrary to Kingdom's value and can only stop by changing our attitude. Our attitudes and mode of relation in the community should be informed by God's will which demands justice and sharing in fellowship. K.C. Abraham upheld justice as the key for liberation. He wrote:

Prophets bring to our awareness the concept of compassionate love as integral to justice. For them a just relationship is possible only if all are included and cared for. Therefore the test of justice is how society treats the most vulnerable sections. They are not asking for charity, but they demand, in their own way, justice and participation. Justice that includes compassion is a necessary correction.¹⁶

First, K.C. Abraham argues that PWDs should organise themselves and fight for their rights. He further states that:

"The disabled are denied their basic human rights and they are excluded from society. To restore their dignity is to struggle for it... But in the case of mentally challenged, they are not capable of organising themselves. In solidarity with them, caregivers and others should create an awareness of their hurts and struggle for their rights."¹⁷

¹⁶K.C. Abraham, "Theological Education and Disability" in *Disability Discourse for Theological Institution* ed by Wati Longchar (Jorhat: ETE-WCC/CCA, 2006), 14.

¹⁷*Ibid.* 14.

Second, PWDs often suffer from unexpected illness, the death of a loved one, accident, lost of job among other pain. When we experience such suffering, we ask ‘why Lord’? When a child is born with physical impairment, we ask ‘why Lord’? Job strongly rejected the idea that suffering is God’s punishment (Job 19:1ff)

Innocent suffering or physical impairment is often explained in terms of “virtuous suffering”. Nancy L. Eiesland criticised the position that physical impairments were a sign of divine election by which the righteous were purified and perfected through painful trails. Such a view supports the notion that “disability as a temporary affliction must be endured to gain heavenly rewards.”¹⁸ She further writes that:

The biblical support of virtuous suffering has been a subtle, but particularly dangerous theology for persons with disabilities. Used to promote adjustment to unjust social situations and to sanction acceptance of isolation among persons with disabilities, it has encouraged our passivity and resignation and has institutionalised depression as an appropriate response to ‘divine testing’. Viewing suffering as a means of purification and of gaining spiritual merit not only promotes the link between sin and disability but also implies that those who never experience a “cure” continue to harbour sin in their lives. Similar to the practice of emphasising self-sacrifice to women, the theology of virtuous suffering has encouraged persons with disabilities to acquiesce to social barriers as a sign of obedience to God and to internalise second-class status inside and outside the church.¹⁹

The idea of virtuous suffering encourages submissiveness to an unjust system in the false belief that whatever happens is the will of God. This idea has insulated us from recognising socio-cultural injustices for what they are and struggling to change the system. The experience of suffering should lead us to fight for justice and dignity.

¹⁸Nancy L. Eiesland, *The Disabled God: Towards a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994), 72.

¹⁹*Ibid.* 72-73.

CHAPTER FIVE

One in Christ: Priesthood of the Disabled and the Exercising of Gifts

C. B. Peter

*“...we have a great high priest who has gone through the heavens,
Jesus the Son of God...”*
(Heb 5:14)

*“He had no beauty or majesty to attract us to him,
Nothing in his appearance that we should desire him...”*
(Is 53:2)

Introduction

Should the church ordain people with disabilities (PWDs) as priests? It is easier to answer that question in ‘yes’ or ‘no’ than knowing why we are saying ‘yes’ or ‘no’. This Chapter seeks to analyse and deconstruct the disability debate in the church and highlight various issues that need to be resolved before we can understand why the priesthood of all believers is incomplete without the priesthood of PWDs.

Should We or Should We Not? The Disabling Error of Normative Approach

Theologians are used to liberally preaching, teaching, and churning out all kind of advice. They have smartly divided themselves into

two camps: the conservative and liberal. The camps can also be referred to as the ‘no’ and the ‘yes’ camp. Both of these camps compete in advising the world about the nature of God and of religion and religious beliefs.

Conservative View

Conservatives in general belong to the “no” camp, and are against ordination of PWDs. Their univocal answer to the question of the possible priesthood of PWDs is a plain ‘no’. Their most-loved biblical text is Lev 21:16-23:

The LORD said to Moses, “Say to Aaron: ‘For the generations to come none of your descendents who has a defect may come near to offer the food of his God. No man who has any defect may come near: no man who is blind or lame, disfigured or deformed; no man with a crippled foot or hand, or who is hunchbacked or dwarfed, or who has any eye defect, or who has festering or running sores or damaged testicles. No descendent of Aaron the priest who has any defect is to come near to make offerings made to the LORD by fire. He has a defect: he must not come near to offer the food of his God. He may eat the most holy food of his God, as well as the holy food; yet because of his defect, he must not go near the curtain or approach the altar, and so desecrate my sanctuary. I am the LORD, who makes them holy.

These crusaders who hasten to cite the above text in defending non-ordination of PWDs ignore the following:

- ◆ That the biblical text cannot, and should not be quoted out of context. The above verse refers to a historical context as precise as the patriarchal custom of marrying their first cousins.
- ◆ That the regulations that guided both the temple and priesthood as institutions in Judaism and Christianity are now obsolete.
- ◆ That hiding behind the scripture to further personal whims is a common human phenomenon as evident in debates on economic ideology, gender, sexuality, and race.
- ◆ Selective appropriation of the scripture to settle ideological debates in one party’s favour raises serious ethical issues. The

whole of the scripture should be referred to when putting forward certain arguments and justifying positions.

Conservatives are not persuaded by the above standpoint. They continue with their whimsical opposition to the ordination of PWDs. Prof. Nancy Eiesland, a leading disability theologian of our times relates the story of Connie Panzarino, a young girl with a disability living in New York. One day, Connie asked her catechist, "When I grow up, can I become a nun like you?" "No darling," came the reply, "I am afraid that to be a nun and to serve God, you have to be able to walk and take care of yourself" (Cited in Leone and Thornburgh, 2003: 105). Eiesland has used this story to depict the attitude of the community of faith in general towards PWDs exercising their gifts to serve God. No wonder we see very few churches sponsoring any PWDs for the ordained ministry. The Rev. Dr. Harold H. Wilke, whom W. Daniel Blair calls "the grandfather of practical ministry literature related to people with disabilities" (Blair, 2003: 76), in his celebrated article "Access to Professional Education" (1978) notes as follows:

The practice of Protestantism, while not canonical, is pervasively negative: the vice-president of [a major grant making foundation] reports, "I cannot remember a single minister in the California Conference of the Methodist Church with physical disabilities; and with admittedly limited knowledge of clergy in the Missouri Conference (United Church of Canada), I cannot recall seeing anyone with physical disabilities." Another minister writes that when he was disabled while serving a congregation, there was "less acceptance for disability, so I resigned" (Wilke, 2003: 14-15).

Dr. Wilke's sentiments as expressed above with reference to the American situation is also true in the African context. We see very few PWDs in our theological institutions being prepared for the ordained ministry of the Church.

Dr. Wilke begins his discourse on the Church's attitude towards the possible ordination of PWDs with a brief examination of the Orthodox and the Catholic Church. The Catholic Canon Law has a

doctrine called “*admiratio populi*” (lit. “amazement of the people”) According to this doctrine, since a priest holds a public office, there should be nothing in his or her appearance that can distract those whom he or she is ordained to serve through preaching, teaching, and administering the sacraments (Wilke, 2003: 12). The implication here is that refusing to ordain a PWD has nothing to do with whether such a person is gifted or whether God wants the person to serve the Church. The denial is purely based on the question: “What will people say?” In other words, it is the people who decide who should, or should not be ordained as a priest.

Liberal View

Liberals advocate for, and support the ordination of PWDs. As a result, we have many PWDs who are ministers in the Church and perform even better than the ‘able’. Robert C. Anderson tells the deeply moving story of a deaf minister who, with the help of a sign language interpreter preached a powerful sermon on the topic “Growing Up Deaf and Hearing the Story of Faith” (Anderson, 2003: 45). Even in the Catholic Church the stance on the possible ordination of disabled persons seems to be somewhat softening up. A statement released by the Catholic Archdiocese of Brisbane states in part as follows:

Like some able-bodied persons, some disabled persons are suitable candidates for the Sacrament of Holy Orders and some are suitable candidates for the Religious Life. However, it should be understood that certain disabilities will always exclude people from entering the priesthood and/or religious life, but the ultimate decision must rest with the local Bishop or Major Religious Superior. (<http://www.TheLiturgicalCommission.htm>. Date accessed 13 June 2008).

While we celebrate the triumph of the liberals in their battle to have PWDs ordained, both the conservatives and liberals suffer from the same disabling error, which I call ‘the socio-cultural objectification of disability’, as discussed below.

The Socio-Cultural Objectification of Disability

The Catholic Canon Law doctrine (*admiratio populi*) as mentioned earlier, militates against the possible ordination of PWDs on the ground that the appearance of a minister with a disability can distract the congregation. This means that the power to make important hermeneutical decisions as to what is the meaning and definition of disability and who are disabled and who are able, lies squarely with the culture and societal thinking.

In such a totalitarian paradigm the society is the subject of hermeneutical decision-making, whereas individuals (be they disabled or able) are the objects. As such it is the society and the culture, which actually relegates certain persons to the periphery by defining them as “disabled.”

Now the vicious circle begins. Having defined certain persons as “the disabled minority,” the society defines itself as “the able majority.” Then it proceeds to ask what shall *we* do about *them*?” What follows is commissioning statisticians to count *them*: Next, social scientists are funded to study *their* attitudes, behavioural patterns and “special needs.” After the study, medical scientists and social psychologists are financed to engineer care delivery systems for PWDs. Equipped with this information, the Church shouts from the rooftop, “Have mercy on *them*.”

And so, as a result of such a rather cruel sociometry, PWDs continue to live in their own small and peripheral worlds, often wondering as to who actually is disabled? They or the society that is unable to accept them the way they are! Nancy Eiesland, while reflecting on her own congenital disability, has noted:

I began to see the “problem” not within my body, but with the society that has made us outcasts, and views and treats us in demeaning and exclusionary ways (Eiesland, 2004: 1).

In a similar vein, W. Daniel Blair, who has titled his section “What shall *we* call *them*?” refers to the postmodernist constructivist theory (Foucault, Butler, Harraway, Corker and French) and argues that:

The language, or more precisely, the discourse that has grown up around the concept of disability is the actual disabling factor for individuals whose physical, mental or behavioural characteristics vary from the socially constituted ideals of “normalcy” (Blair, 2003: 71).

Brett Webb-Mitchell clearly identifies the problem of disability within the society and the culture when he observes that:

Of course, a disability is whatever a particular group of people defines as a disability. In other words, every disabling condition is a cultural invention or social construction rather than personal or private problem (Webb-Mitchell, 1996: 126 cited in Blair, 2003: 71).

Robert C. Anderson has drawn our attention to everyday conversations laden with socially constructed meanings, for example:

- ◆ “A woman’s place is in the home.”
- ◆ “You’ll have to go to the back of the boy” (white bus conductor telling a black boy).
- ◆ “He’s crippled.”

Anderson further states that:

Note how the phrases define “normal” by presenting what is not desired (deviance or abnormality). These images expose cultural biases and transform words into value-laden “norms.” Michele Foucault identified this process as the primary means by which a dominant culture inscribes its values onto the human body. To extend Foucault’s analogy, one is not born “black” or “a woman” or “disabled.” These signifiers are inscribed in relation to some unstated norm such as maleness, being white or being able-bodied (Anderson, 2003: 40)

From the above sequence of citations, it becomes evident that society has largely excluded PWDs from the disability discourses. PWDs

have ended up becoming the mere passive objects of socio-cultural consideration. Let us now consider the popular aesthetics.

“Sensual Beauty is Good”: Our Disabling Aesthetics

It is rather strange that ancient Greek philosophers while doubting the dependability of mere sense perception, defined beauty chiefly in sensual terms. Furthermore, they equated such sensual beauty with moral goodness. Brazilian scholar Charles F. Eitosa notes as follows:

If the Greek culture was marked by the ideal of “kalos-kagathos”, that is, a correspondence between goodness and beauty, one could say that there would be such thing as a non-explicit ideal of “kakos-kaischros”. With this neologism, which juxtaposes “kakos” [bad] and “aischros” [ugly], I intend to show the necessary connection between ugliness and iniquity. On several occasions, Plato criticised Homer for not showing properly the gods’ and heroes’ beauty. For example, in many passages he affirms there is a relationship between the lack of grace, rhythm or harmony and the bad conduct or bad speeches (See Politeia; III, 401a; Gorgias; 470e). (<http://www2.eur.nl/fw/hyper/IAA/Yearbook/iaa5/feitosa.pdf> dated accessed 12 June 2008).

The association between sensual beauty and moral goodness as mentioned above is shared by almost all cultures in the world, both ancient and modern. I suppose that a physically ugly person would hardly impress an audience, an interview-board, or a prospective suitor. However, while it might seem easy to equate physical ugliness with moral evil, it would not be equally easy to assume that the contrary is true.

For example, can we say that a good looking and physically healthy person has necessarily an equally good moral character? Maybe! Maybe not! At this point, I salute the fine arts (painting, music, and literature) for grappling with the intricate issue of the relationship between aesthetics and morality. Art serves as the mirror of life. To understand the life of a certain civilisation in a certain era, we need to study its art forms –paintings, songs, dance, drama, and

stories. We may thereafter note that people in the middle ages associated physical ugliness with moral evil. The villains were depicted as unattractive ruffians wearing eye-patches. Witches were depicted as ugly old women with crooked noses and hunchbacks. Such pictures are common in children's comic books today. It is no wonder our children grow up with sub-conscious notions of associating disability with evil.

Let us return to the earlier question. Can the contrary be equally true? Is physical beauty and a perfect healthy body proof or an indicator of moral goodness? Once again, we may use the artistic angle. Look at the list of infamous persons from the last century – Adolf Hitler, Benito Mussolini, Joseph Stalin, Pol Pot, and Agostino Pinochet. They were all able-bodied and handsome men. None of them can be described as a PWD. And yet they were embodiments of evil. We all know that they engineered wars that degenerated into ferocious bloodshed. Closer home, what about our African brethren – Mobutu Sese Seko, Idi Amin, and Which one of them was disabled or ugly? Were they not all very able-bodied, healthy and handsome men? And look, what they have done to our continent!

The artistic mass media have brought home this quite forcefully. Dame Agatha Christie, the renowned English crime writer of the 20th century, in many of her novels assigns most unlikely characters the evil role – able-bodied beautiful women and handsome men. More recently on a Nation TV in Kenya there was a serial programme named “Rubi” who's most villainous character is also the most beautiful.

For those who do not read crime novels or watch soap operas, just read the Bible and you will find that the fruit that caused all this havoc in this world was not disabled, rotten, poisonous or ugly. On the contrary, it was “good for food and pleasing to the eye, and also desirable for gaining wisdom” (Gen 3:6). In the book of Proverbs, the thought that sensual beauty entails deadly evil is repeatedly made known through powerful imagery in the loving father's advice to his son to flee from wine and woman:

Do not gaze at wine when it is red,
When it sparkles in the cup,
When it goes down smoothly!
In the end it bites like a snake,
And poisons like a viper (Prov 23:31).

In Proverbs 7 there is the moving depiction of a young man being tempted by a very beautiful woman. The woman is not ugly or disabled. In contrast, her appearance and even her bedding are described in the highest aesthetic terms. And yet she embodies evil and an inescapable death for anyone foolish enough to follow her.

And at once he followed her
Like an ox going to the slaughter
Like a deer stepping into a noose
Till an arrow pierces his liver,
Like a bird darting into a snare,
Little knowing it will cost him his life (Prov 7: 22-23).

The damnation of sensual beauty continues in the New Testament as John echoes in his first epistle:

For everything in the world – the cravings of sinful man, the lust of his eyes and the boasting of what he has and does – comes not from the Father but from the world (1 Jn 2:16).

Now let us look at the contrary – does the Bible equate physical ugliness with moral evil? The logical answer (considering the non-equation of sensual beauty with moral good) is *'no', it does not*. I have attempted to show this in the scripture I used as an epigraph to this presentation. Jesus Christ is our majestic and merciful High Priest. And yet his majesty and beauty is manifested in his ugliness and disability.

He had no beauty or majesty to attract us to him,
nothing in his appearance that we should desire him.
He was despised and rejected by men,

a man of sorrow and familiar with suffering.
 Like one from whom men hide their faces
 He was despised and we esteemed him not.
 Surely he took up our infirmities and carried our sorrow,
 Yet we considered him stricken by God,
 Smitten by him and afflicted.
 But he was pierced for our transgressions,
 He was crushed for our iniquities;
 The punishment that brought us peace was upon him,
 And by his wounds we are healed (Is 53:2-4).

We may add Nancy Eiesland's magnificent exposition of the resurrection narratives where the glorious and the resurrected Lord appears as disfigured and disabled to the Song of the Suffering Servant, the book of Job, and the central Christological events of the Incarnation and the Cross. Careful consideration of these writings shows that the Bible does not equate physical ugliness with moral evil. This wraps up our case that beauty and ugliness as mere physical conditions do *not* equate with the corresponding moral virtues of goodness and evil. If anything, there seems to be a contrary relationship between the sensual and the moral, that is, physical beauty is associated with moral evil and ugliness, whereas physical ugliness and disability is associated with moral good and beauty.

A Postscript to the Theology of Disability

During the past 30 years or so we have developed a robust and vibrant theology of disability, which according to the excellent literature review by W. Daniel Blair (2003: 73-77), may be divided into three major streams as outlined below.

First, there is a renewed focus on the human body. The orthodox theological framework was based on the God-man-sin-salvation schema, while the theological method was mainly deductive and didactic. Any reference to the human body was at best treated in a footnote or, perhaps, in a subsection. Perfection of the body was assumed as symbolic of the perfection of the soul as taught by Philo (See Wilke, 2003: 10). According to the ancient Jewish scholar

Moses Maimonides, the multitude “does not appreciate a man for his true worth, but for the perfection of his limbs and the beauty of his garments” (cited in Wilke, 2003: 10).

But the theology of disability has challenged the orthodox “doctrinal” framework. It has actually made the human body a subject of renewed and refreshing theological reflection. Nancy Eiesland, for example, counters the myth of the bodily perfection (Eiesland, 2004: 2), which would mean that *no* human body – whether able, temporarily able, or disabled – is perfect. Consequently, we can *no longer* divide human beings into the demeaning and dehumanising categories of the “able” and the “disabled.” Indeed, we are *all* disabled and need help in one way or another. Major contributors to the body theology are: James B. Nelson (1992), Elizabeth Moltman-Wendel (1994), Deborah Creamer (1995), Mary Timothy Prokes (1996), L. Isherwood and E. Stuart (1998), and E. F. Rogers (1999).

Second, there is the remarkable emergence of what I may call “the disability Christology” which differs from the traditional type. The traditional type of Christology was taught (and is still taught) through the doctrines of the person and work of Christ. The disability Christology, on the other hand, is an existential type of Christology where any human being in the context of her or his disability identifies with Christ as the “Disabled God.” The major contributor to this stream of thought is Nancy L. Eiesland, who in her thought-provoking book *The Disabled God* (1994) has drawn our attention to the oft-ignored fact that the glorious body of the resurrected Christ is disfigured and disabled in that it still bears the marks of crucifixion.

Third, there is the practical theology stream, which challenges the attitudinal, architectural, and liturgical barriers that fail to provide equal opportunities to all members of the community of faith in the worship and common life of the Church. The pioneering contributor to this stream is Harold H. Wilke (1980, 1999). Other major contributors are: Brett Webb-Mitchell (1994, 1996), Stuart D. Govig (1999), and Gene Newman and Joni Eareckson Tada (1981, 1993).

To the above three streams, we may add three more. First, is Burton Cooper’s advice that the idea of God’s “perfection” must be interpreted in Christological light. This means that if Christ is the *only* way by which we may know God, then the same Christ for

our sake cuts the image of the imperfect PWD and disfigured. Therefore, God's perfection should be something other than what the dictionary defines as "perfection" (Cooper, 1992).

Second, there is the question of theodicy. Why does God allow all this to happen (Cooper, 1992)? But, such a question is only valid if it comes from PWDs themselves. Not from others wanting to shower PWDs with unsolicited sympathy. Third, there is the issue of what John C. Ward calls "a theological anthropology". This consists of a critical reflection on the real life stories of men, women and children with disabilities (Ward, 2000).

It is necessary to further discuss my postscript on the theology of disability. The topics discussed below should be included in the disability theology curriculum.

Redefining Disability

We cannot settle the debate on whether or not PWDs should be ordained into priesthood without re-examining the whole process of defining disability. I call it "the whole process" because defining disability is not just a lexical or semantic matter. It is a socio-cultural process. I have already discussed how PWDs have been made objects of moral consideration in society. We have seen how the so called "able majority" has abrogated to itself the right to define disability.

We have definitions of disability that range from the derogatory to the sympathetic. Examples include: crippled, impaired, handicapped, retarded, differently able, the disabled or people with special needs. These definitions emerge from three core assumptions.

First, the assumption that the power to define human beings on the basis of their physical condition rests solely with the so called "able-bodied" majority. Second, that disability is defined by virtue of a condition that is found in the bodies of certain human beings. Third, that disability is defined by economy. To illustrate this last assumption, I refer to the medical definition of disability. It states that someone is deemed disabled if he or she cannot participate fully in the Activities of Daily Living (ADL). In other words, someone is disabled if he or

she cannot earn an income and thus depends on others for survival (cf. Anderson, 2003: 40). Such a subjective, conditional, and economic approach to defining disability has prompted scholars like Nirmala Erevelles to come up with a better definition:

The working definition of disability I was using was any observable physical and/or mental impairment that is identified as the means to exclude individuals from participating in mainstream life. In saying this, I was challenging the medical model that located the disabling condition within the individual rather than in the oppressive social contexts within which the disabled individual lives (Erevelles, 1998: 6).

As Blair rightly commends, “By employing this definition, Erevelles highlights both the ambiguity and the subjectivity of the term” (Blair, 2003: 72).

In my attempt to offer a definition of disability, I have tried to rise above the three barriers of subjectivity, conditionality, and economy by offering the following:

Disability is the situation of being unable to do something, which the intending doer wants to do.

My definition above highlights three things: first, disability arises out of a situation in which we are, and *not* a condition which is in us. Second, since disability arises out of a situation or a context, we are **all** disabled in one way or the other. No human being, whether a man, woman, or child – has ever walked this earth who was able to do everything that he or she ever wanted to do. There is no true dichotomy between the so called “able” and “disabled.” Most disabled people are able to do most of the things that their “able” counterparts claim to be competent at even more exceptionally.

On the other hand there is no “able-bodied” person in this world who does not suffer from some form of “limitedness” as Deborah Creamer prefers to call disability (Creamer, 2003: 64-66). A due recognition of the permanence and universality of the disability factor

will help in correcting the socio-cultural error of objectifying disability and dividing the society into mutually exclusive classes.

Third, a correct definition of disability involves the intending doer, and *not* someone who watches at a safe distance. This means that only PWDs have the right to define their own disability, and choose whether they should in the first place deem their condition a “disability” at all. The story of two little boys who were taught by their mother that it is a good thing to help old people cross streets illustrates this important point. After their escapade, they returned home late in evening to a worried mother. Cheerfully, they told her, “Today we helped a very old man to cross the street.” The mother was almost tearful with joy. “My darling angels,” she cried out as she smothered her boys with kisses, “I am so proud of you. But tell me, please. What took you so long in returning home?” “Because,” chirped the boys, “The old man *did not want* to cross the street.” This story illustrates the guilt of our society, which has assumed that all people, whose bodies are differently made, consider themselves as “disabled” and are looking for “help.” Who gave us the right to define other people’s conditions and decide that they are “disabled” and need our “help”?

One of the most unfortunate and unjust judgements that the so called “able bodied” people have made is to assume that all PWDs live in a state of self-pity and are “crying for help.” Such seems to be the general assumption of most faith-healers. Fine, those that are crying for help need to be helped. But, what about millions of PWDs who happily define their own “normalcy” and “wholeness” as incomplete without their disability? Arne Fritzson narrates about a character with cerebral palsy in a Swedish movie. When he was asked if he would want to get rid of his impairment in a second life, he replied, “Without it, I would not be me” (Fritzson, 2004: 14). This movie character mirrors the real situation on the ground. Deborah Creamer considers her disability as an inseparable part of her own “wholeness” and is not keen to live without it even in heaven (Creamer, 1995: 83)!

My own second born daughter Monica Roselyn Peter suffers from Down’s syndrome. Now at 30, she still looks like a teenager, and is very smart! When I asked her last year if she would like to go

to a special school once again, she told me clearly, “Forget it, dad. The problem is not with me; it is with other people. They will think I am mad. I am doing just fine at home.” And if you offer our eminent host Mr. Samuel Kabue to take him to a faith healing crusade to “help” him regain his sight, he might respond in a similar vein (Kabue, 2004: 36-40).

Redefining Wholeness, Normalcy and Perfection

Our traditional definitions of wholeness, normalcy and perfection are driven by the assumption that disability is a temporary condition afflicting a minority who are on the socio-cultural periphery. Thus we define perfection, wholeness, and normalcy as a condition where any disability, defect, ugliness, impairment, or blemish is permanently absent. Since we cannot find such a condition in the real world easily, we ascribe it to God and Heaven.

However, there is need for a serious revision of our traditional definition of perfection, normalcy, and wholeness. This is especially urgent, given my argument for the universality of disability, and disability theologians like Nancy Eiesland and Burton Cooper’s convincing view of a disabled God.

We need to redefine perfection in terms of completeness and equilibrium. This will take us back to the theology of creation. God created a complete universe and a complete life. Nothing would be complete without the mutually complementing pairs of opposites (light and darkness, hope and despair, joy and pain, positive and negative, yes and no, hard and soft, beautiful and ugly, sweet and bitter, ability and disability, and so on). If you remove one set (say the negative attributes) out of this equation, you will disrupt the equilibrium. As a consequence, the creation will no longer be complete. St. Paul puts it beautifully in his exposition of the body (a core theme of disability theology):

Now the body is not made up of one part but of many. If the foot should say, “Because I am not a hand, I do not belong to the body,” it would not for that reason cease to be part of the body. And if the ear should say, “Because I am not an eye, I do not belong to the body,” it would not for that reason cease to be part of the body. If the

whole body were an eye, where would the sense of hearing be? If the whole body were an ear, where would the sense of smell be? But in fact God has arranged the parts in the body, every one of them, just as he wanted them to be. If they were all one part, where would the body be? As it is, there are many parts, but one body (1 Cor 12: 14-20).

By extending St. Paul's argument to the whole creation, we may look at the creation and the life of the world as the body, and the opposite but complementing experiences of joy and pain, beauty and ugliness, etc., as various "parts" of the body. We may now reconstruct Paul's argument as follows:

Life is not made up of one experience but of many. If disability should say, "Because I am not ability, I do not belong to life," it would not for that reason cease to be part of life. And if ugliness should say, "Because I am not beauty, I do not belong to life," it would not for that reason cease to be part of life. If the whole life were ability, where would disability be? If the whole body were joy, where would the sense of pain be? But in fact God has arranged the experiences in life, every one of them, just as he wanted them to be. If they were all one experience, where would life be? As it is, there are many experiences, but one life.

Redefining perfection, wholeness, and normalcy as completeness of the opposite but mutually complementing experiences would mean that we cannot take life as complete and perfect without the necessary experience of disability.

As a young boy, I had an experience that changed my worldview a long time ago. One day I was digging on a piece of our farm. Suddenly, I realised to my disgust that I had cut a worm in half. It made no noise or resistance. It died just like that, silently. It appeared quite harmless and useless. And I said to myself, "Why did God create this worm? What purpose is it serving in creation? How is it contributing to enrich our life? I could not find an answer then. But, when I now look back to that incident, I see the answer. "Surely that worm was serving some great purpose assigned to it

by God in His great creation.” I do not have to know all of God’s purposes. But I am sure of one thing: if I proceeded on a billion dollar project to destroy all the unfamiliar, unknown, and ugly worms from the face of the earth, I will only end up destroying God’s creation. This is effect may render the earth unfit for farming and habitation.

Therefore, life cannot be normal, perfect, and whole without the necessary experience of disability. The theology of disability can and should borrow a leaf from the process of theology which holds that the totality of life comprising opposites but mutually complementing experiences all exist in God (pantheism).

Exploring a Disability Aesthetic

Our earlier arguments in this Chapter compel and inspire us to explore a disability aesthetic to integrate into our theology of disability. The disability aesthetics would be as different from traditional theoretical aesthetics as disability theology is from the traditional dogmatic theology.

In such aesthetics we should no longer analyse the aesthetical theories of Kant and Schiller, but rather focus on the cardinal question of what really makes something “beautiful” and another “ugly” and why? Are beauty and ugliness absolute categories? Are they relative to socio-cultural contexts? What really is “ugly” about it if: one of my hands is shorter than the other, I have only one hand, I have three hands instead of two, or no hands at all, for that matter? Who has the power to define what size, shape, or number qualifies in the category of the “beautiful”? It would also study the question as to which concept of “beauty” inspired such radical schools in art as asymmetrical design, abstractionism, impressionism, and surrealism? Furthermore, the disability aesthetics would explore the relationship between sensual beauty and ugliness and moral good and evil, as discussed above. It will also critically examine the treatment of physical disability in art, literature, music, and the mass media.

Reflecting on Disability as Vicarious

One day, while I was walking the streets of Eldoret, Kenya, I came across a man without legs begging by the roadside. I asked myself (like the disciples of old): “What did this man do that he was deprived

of the privilege of walking tall like others? What kind of an existence has he been subjected to? Will he be able to live life to the full? Will he be able to find a wife and bear children to carry his name?" And then, I thought about myself: "What good have I done to deserve an able body?" And, with a sense of guilt and horror, I realised that I had not done any particularly good thing to deserve an able body. I remembered all the bad things that I had done in my life and the people I had hurt. I then realised that I did not deserve my able body. And I said to myself, "What if I were like this man?" What would stop God from making me like him and him like me? And then a strange question came to my mind, "What if this man has taken my place in God's mysterious plan of vicarious suffering? What if he has been made legless so that I may walk? What if he is doing for me what Christ did for the whole world?" These words are better captured in the book of Isaiah:

Surely he took up our infirmities and carried our sorrow,
Yet we considered him stricken by God,
Smitten by him and afflicted.
But he was pierced for our transgressions,
He was crushed for our iniquities;
The punishment that brought us peace was upon him,
And by his wounds we are healed (Is 53: 4-5).

Incidentally, our current theology of disability uses the reflections of PWDs on their own situation more, rather than reflections of the so called "able bodied". The theology of disability can be enriched by an inclusion of such reflections where the able bodied might reflect on the vicarious suffering of Christ and declare, "There are blind people in this world so that we may see, there are deaf people so that we may hear, there are legless people so that we may walk. We do not deserve our able bodies; we owe our bodies to our disabled brothers and sisters."

The Way Forward: Some Recommendations

The following recommendations emerge from what I have offered above:

1. We should re-conceptualise human society as one common family of men, women, and children where *all* are considered as disabled in one way, and able in another.
2. We should unlearn our previously acquired definitions of beauty, ugliness, perfection, wholeness, normalcy, ability, and disability.
3. There is need for a curriculum renewal in all theological faculties so that theology of disability is not relegated to the periphery as a “theology of the disabled, for the disabled, and by the disabled.” Instead the disability theme should be integrated into the mainstream while designing curricula in theology, ethics, philosophy, and biblical exegesis.
4. And finally, physical access to all places by all people should no longer be regarded in terms of “a special need” of some people, but as an essential need of *all* people. Therefore, as we build our churches, colleges, universities, and other places, we should as a matter of necessity consider the wants of PWDs. Perhaps they should be co-opted in building committees and architectural consultations. Inclusion of ramps, lifts, better lighting and acoustics in buildings, and the provision of sign language interpreters, Braille facilities, and support service providers to PWDs should no longer be regarded as a mere cosmetic luxury. It is our moral responsibility. We *all* are disabled, and at the same time, we *all* are able to assist one another.

Conclusion

The Chapter has examined the issue of the priesthood of PWDs in the broader light of the entire disability debate. It has disentangled various issues that require resolution in order for PWDs to be ordained as priests.

Priesthood of all believers necessarily includes priesthood of PWDs. It is in having disabled priests that the church can bring glory to the Lord Jesus Christ, our Merciful and Disabled High Priest.

Disability, Society, and Theology

CHAPTER SIX

Biblical Perspectives on Disability

Sammy Githuku

Introduction

This Chapter examines disability from a Biblical perspective. Like many other aspects in life disability was not mysterious in the biblical times. Whereas different forms of bodily disabilities are mentioned, some are not identified with certainty. Since the bible extensively uses figurative language in reference to disability, this is evidence that the effect of disability to the lives of people in those times was significant. In order to appreciate the biblical understanding of disability, we shall first look at today's definition of disability. Thereafter, we shall scrutinise different types of disabilities mentioned in the bible and the attitude of the population towards people with disabilities (PWDs). Lastly, we shall explore how Jesus and Paul in the New Testament revolutionise the dated biblical perspective on PWDs.

What is a Disability?

The language and terminology of disability has evolved over the years. Disability is now defined in several ways depending on the discipline and sometimes the country. Some communities are more sensitive than others when choosing words to describe disability or refer to PWDs. Since this Chapter offers a biblical perspective and, Let us consider some of these disabilities in detail.

For no one who has a blemish shall draw near, a man blind or lame, or one who has a mutilated face or a limb too long, or a man who has an injured foot or an injured hand¹, or a hunchback, or a dwarf, or a man with a defect in his sight or an itching disease or scabs or crushed testicles.

The original Hebrew word that is translated to mean “blemish”² in English, for example signifies no particular skin disease. It is used generally for any and all disfiguring afflictions of the skin (Lev 24:19, 20). Similarly, looking at the translation, disabilities regarded as “injured hand”³, “dwarf”⁴ and “defect in his sight”⁵ are not specific. Even in cases where apparent specific disabilities are stated such as visual, hearing or physical; these words could as well be referring to different types of sicknesses today. Other forms of disabilities mentioned in the bible include left-handedness and mental disability. Let us consider some of these disabilities in detail.

Types of Disabilities Mentioned in the Scriptures

Physical Disability

The bible does not define the term disability as alluded to in contemporary definitions as shown above. Instead, it describes different types of handicaps. Since these disabilities are not the subject in the biblical text, they are in most cases implicitly mentioned. The following is an outline of these disabilities.

¹*sheber regel sheber yad* – ‘broken foot and hand’ (NRSV), ‘crippled foot and hand’ (NIV).

²*m’uwm* – means any physical, stain or moral defect.

³*sheber yad* – ‘broken hand’ (NRSV), bruised.

⁴*Daq* – “a withered” or “a very thin person”, “a dwarf” (KJV), “small”.

⁵*taballul ayin* – “a discoloured spot or streak in the eye” (Wenham, 350), “any eye defect” (NIV).

Visual Disability

Visual disability is the most mentioned form of disability in the Bible. Unlike today where science differentiates types of eye diseases, the word commonly translated as “blind” was used to refer to a variety of different types of eye diseases in biblical times⁶. It is clear from the scripture that any form of eye disease that caused inability to see completely or blurred vision meant visual disability. Judging from the frequent mention of the word “blind” in the Bible, it seems that visual disability was a common and serious problem in that age.

There is very scanty information in the bible on how visual disabilities were acquired. However, we note that some forms of disabilities developed from birth (Jn 9:1). Advanced age was also responsible for physical, mental and visual disabilities. For example, at old age Isaac could not see although he could hear clearly (Gen 27:1); at ninety-eight years, Eli could not see (1 Sam 3:2, 4:15). Similarly, due to an advanced age prophet Ahija could not see (1 Kgs 14:4). This blindness of old age was probably from senile cataract.

Elsewhere, the Bible talks of miraculous interventions that resulted in temporary or permanent visual disability. The smiting of Paul (Acts 9:8), Elymas (Acts 13:11), and the Syrian soldiers (2 Kgs 6:18) are by miraculous intervention. The angels of the Lord struck the men of Sodom with visual disability so that they could not find the door to Lot’s house (Gen 19:11). Visual disability was also acquired through human punishment. Causing visual disability on war captives was a common form of punishment in other nations surrounding Israel (1 Sam 11:22; Kgs 25:7). However there is no evidence that such methods were used in Israel. Divine punishment also resulted in visual disability (Ex 4:11; Deut 28:28).

⁶*Amblyopia*, dimness of vision, *Blepharitis*, an inflammation of the margins of the eyelids, *Cataract*, the eye becoming progressively opaque, *Chalazion*, a small tumor which develops on the eyelid, *Conjunctivitis*, a membrane that lines the undersurface of the eyelid.

The attitude towards people with visual disability is made explicit in the figurative use of visual disability as spiritual disability. It is used in the sense of obscuring spiritual perception (Jn 12:40). Figuratively, visual disability is used to represent want of mental perception, recklessness, and incapacity to perceive moral distinctions (Is 42:16, 18, 19; Mt 23:16 ff; Jn 9:39 ff). Visual disability is a constant image used to refer to spiritual darkness. Therefore, Jesus' restoration of sight to the blind pointed to the analogous spiritual bestowal of sight on the soul. Paul, who had passed through both the physical and the spiritual transition from darkness to light (Acts 9:8, 9), instinctively, by an obviously undersigned coincidence confirming authenticity, often uses the expressive image (Acts 26:18; 2 Cor 4:4; Eph 1:18; 4:18; Col 1:13). Metaphorically, this word can designate a helpless and morally insensitive person. False prophets (Is 56:10; Lam 4:4) and the nation of Israel (Is 42:19; Is 43:8) are characterised as 'blind'. Israel laments its blind condition (Is 59:10). The promise of the restoration of the remnant includes God's leading the blind in their return to Zion and restoring their sight (Is 29:18, 35:5, 42:16; Jer 31:8).

Speaking Disabilities

People with difficulties of speech are also considered as having a disability in the bible. Speaking disability is used literally to refer to the condition of speechlessness or stammering. There are several causes of speaking disability recorded in the scripture. First, it could be a sign of a divine call. Temporary speaking disability was inflicted upon prophet Ezekiel as a sign of his calling (Ezek 3:26; 24:27; 33:22). Second, individuals who had speaking disability were thought of as stricken by God (Ex 4:11). Zechariah was stricken and could not talk as a punishment for his disbelief (Lk 1:20, 64). In the New Testament, people with speaking disability were thought to be possessed by an evil spirit. There are several recorded cases of Jesus healing people with speaking disability by casting out demons (Mt 15:30; Mk 7:37; Lk 11:14).

Speaking disability is also used figuratively to refer to the silence produced by the weight of God's judgments (Ps 39:2-9; Dan 10:15). It also refers to the oppression of external calamity (Ps 38:13). As an adjective, it is used to describe inefficient prophets and teachers of Israel: "they are all dumb dogs, they cannot bark; dreaming, lying down, and loving to slumber" (Is 56:10). Dumb dogs cannot roar and hence they are useless. The companions of Saul were so frightened by the incidence of Paul's conversion on the road to Damascus that they stood speechless (Acts 9:7). Similarly the man without the wedding garment was speechless because he had no excuse to give (Mt 22:12). Idols are ridiculed because they are voiceless (Hab 2:18, 19; 1 Cor 12:2). The dumbness of the sheep before the shearer is a gesture of submission (Is 53:7; Acts 8:32).

Often, a person with hearing disability may also have speaking disability (Mk 7:32, 9:25). Healing involved loosening the string of his tongue probably tied by the demons (Mk 9:25).

Hearing Disabilities

We also encounter narratives of people with hearing disability in the bible. Like visual disability, hearing disability was used literally to refer to the inability to hear. It is also used figuratively to refer to moral insensitivity (Is 6:10, 29:18; Mt 13:15). The biblical world was short of the explanation of what caused hearing disability. It was regarded as divine judgment from God (Ex 4:11; Deut 28:28; Mic 7:16). In New Testament times, hearing and kindred defects were attributed to evil spirits (Mk 9:25).

Physical Disability

The bible also contains narratives of people who were singled out of society because of their physical disabilities. These included short hands (Is 50:2), hunchbacks (Lev 21:20), unequal legs (Lev 21:19; Prov 26:7) and those were unable or imperfectly able to walk on their feet (Job 29:15). An injured or disfigured arm is probably what is referred to as a "short hand". Such disability was considered weakening: "And the LORD said to Moses, "Is the Lord's hand

shortened? Now you shall see whether my word will come true for you or not” (Num 11:23). As an adjective, the idiom “short hand” is translated as “feeble” (ASV), “small power” (RSV) and “short of strength” (2 Kgs 19:26; Is 37:27).

Physical disability is used figuratively to express inability. In the prophetic literature, Prophets Jeremiah and Ezekiel described the fullness of the victory and joy of the returning Israelites in terms of physical ability. In returning Israelites will be made whole and shall leap like a deer (Jer 3:18; Isa 35:6). Prophet Isaiah speaking against the Assyrians also figuratively describes the unfit and inability of the physically disabled (lame) to participate for warfare. The defeat of the Assyrians will be so great that even the people with physical disabilities will take prey (Is 33:23). Job in his graphic description of his helpfulness to the weak before his calamity says, “*And feet was I to the lame*” (Job 29:15). The Philistine warrior from Gath, Israel’s archenemies is said to have ridiculed the Lord. To stigmatise him, his unusual physical features that were understood as physical disability are described: “*he had on every hand six fingers, and on every foot six toes, four and twenty in number*” (2 Sam 20:21, 1 Chr 20:6). In ridiculing him further, the writer points out that he was a giant, yet Jonathan the son of Shimea killed him.

Physical disability, like other forms of disabilities we have considered above was also attributed to divine punishment. “The Lord will strike the people who break the covenant with different types of disabilities” (Deut 28:28). However, it may also have been acquired from birth. Injuries and accidents may have been further causes. Mephibosheth, Jonathan’s son had his both legs injured in an accident during his childhood (2 Sam 4:4, 9:3).

Left-Handedness

There is not much reference to left-handedness as a disability, but the little information we get from the Old Testament and the New Testament reveals that left-handed people were also regarded as people with disability. This disability was acquired from birth. Left-handed people were spoken of as “impeded on the on the right

side” (Judg 3:15, 20:16). The fact that Ehud was left-handed allowed him to carry out his plan for the assassination of Eglon. The guards would have noticed that he had no dagger on his left hip (the usual place). He, being left-handed, had it at his right side, easily concealed. Ehud however may have been one of the seven-thousand men who could use both hands (1 Chr 12:2).

To give the right hand was a pledge of fidelity and submission to the victors (2 Kgs 10:15, Ezra 10:19, Jer 50:15, Ezek 17:18). “At the right hand of God,” is the place of honour, power, and happiness (Ps 16:11; 45:9; 110:1; Mt 26:64; Col 3:10). The right hand is a symbol of skill, energy, and action. On the contrary, the left hand is a symbol of powerlessness and weakness. However, the left side, in some cases, merely refers to another alternative from that on the right. (Is 9:20; Prov 3:16). In numerous cases the expression, “to the right hand or to the left,” appears in scripture, describing a straying from the straight path (Gen 24:49; Num 20:17; 2 Sam 14:19).

In the New Testament times, the attitude towards left-handed people is the same as that of the Old Testament times. With reference to the second coming of Christ, it is said that he will separate the sheep from the goats, “and he will put the sheep on his right, and the goats on the left,” declaring to those on the right, “Come, you blessed of my Father, inherit the kingdom prepared for you from the foundation of the world (Mt 25:33-34). The left hand side is therefore for those facing punishment.

Mental Disability

Both in the Old and New Testament, reference is made to people with mental disabilities. It is not clear what this implied. It seems that the sickness of the nervous system, depression, epileptic and personality maladjustments were generally seen as the same disability. The complicated issues in health, social life and personality development that may result in mental disability were unknown that time. In the Pentateuch, mental disability was regarded as a divine punishment inflicted on those who disobeyed the laws of God. “*The LORD will smite you with madness and blindness and confusion*

of mind;” (Deut 28:28). Elsewhere in the Old Testament, it is ascribed to the spirit sent by the Lord. “*Now the Spirit of the LORD departed from Saul, and an evil spirit from the LORD tormented him*” (1 Sam 16:14). In the New Testament, the evil spirit causes mental disabilities (Jn 10:20).

The most common mode of diagnosis seems to be incoherent speech, unacceptable language or unusual behaviour and manners. Jehu used to ride his chariot so frantically that he was described as riding “like a mad man” (NIV), “furiously” (KJV), “like a maniac” (NRS) (2 Kgs 9:20). David’s tactical actions of the spittle falling upon the beard and slavering at the mouth before King Achish border those of a person with mental disability: “Achish said to his servants, “*Look, you see the man is mad; why then have you brought him to me?*” (1 Sam 21:14). Similarly, Paul warns that if the whole church comes together and speaks in tongues without an interpreter, they will be mistaken for being mad (1 Cor 14:23). In the book of Jeremiah, a true prophet was a spiritual man; a false prophet perceived as “a mad man” who pretended to possess a spirit of prophecy (Jer 29:26). Similarly, the sinful Israelites called prophet Hosea “a mad man” for prophesying their imminent judgment (Hos 9:7). Since the later two examples are found among the prophets, it is most likely that the term mental disability was used to refer to inarticulate muttering or ecstatic prattling used by the prophets.

Attitudes towards People with Disabilities in the Scriptures

In most historical cultures, disabilities have often been cast in a negative light. These conditions were seen as disabling. In the bible too, people with different forms of disabilities are discriminated against. The negative attitude towards people with disability can further be deduced from the figurative use of different disabilities in the scriptures. Generally speaking, people with disabilities were seen as misfits and were faced with all types of discrimination both in Old and New Testament societies. There was a stereotype belief that a person with one form of disability was disabled in many other things. People with physical disability, for example, are often mistaken

of having a mental disability. Sometimes, people with disabilities are stigmatised and reduced to the status of, or compared to animals. Furthermore, disability was viewed as a visible divined punishment for sin.

Discrimination in Employment

Today, people with disabilities can do many types of jobs. Many countries have (at least on paper) policies of non-discrimination in recruitment. In the bible, PWDs did not have the same rights as everyone else in the community. In most cases, they were discriminated against in employment. The Mosaic Law prevented them from full participation in social and religious life. Furthermore, the biblical world was very harsh to people with disability. No consideration of the needs of people with disability was made in public places such as the temple. This resulted in indirect discrimination. Besides the protection offered by Mosaic Law, the biblical world had very little or no knowledge of the needs of people with disabilities.

Discrimination Against People With Visual Disability

The blind, for example as we saw in Lev 21:18 were counted as unfit for priesthood. In the Old Testament, the eyes were a criterion of determining beauty. People with “weak eyes” were therefore discriminated against. They were not counted as beautiful like those with ordinary eyes. Leah, for example was discriminated against compared to her sister Rachel because her eyes were “weak” (Gen 29:17)⁷. In other words she was not a beautiful woman because her eyes were the opposite of beautiful and pleasant eyes. In the New Testament, the public attitude towards the blind is explicitly demonstrated in Mt 20:30. In this episode, two blind men are reprimanded by the crowd for calling upon Jesus to heal them.

⁷The Hebrew word *rak*, (weak, tender, faint) is used in derogatory way to contrast Leah from Rachel. (See also Isa 47:1).

Discrimination Against People Hearing Disability

People with hearing disabilities were also discriminated against. In Psalm 58:4, the wicked are compared to the deaf adder: “like the deaf adder that stops its ear” (Ps 58:4). The expression alludes to a curious notion that – the adder, to avoid hearing the voice of the charmer, laid its head with one ear on the ground and stopped the other with the tip of its tail. The erroneous idea probably arose from the absence of external ears. The wicked are compared to the deaf adder. Like the deaf adder, that is, insensible to all the words of the charmer, so are the sinners. The deaf are therefore thought to be insensitive to their environment.

Hearing disability is used figuratively to express the unwillingness to hear the divine message (Ps 58:4), or incapacity to understand it for want of spirituality (Ps 38:13). God’s power to save his people is figuratively demonstrated by the fact that God does not have hearing disability (Is 59:1). The prophetic utterances were sufficiently forcible to compel even such to hear (Is 42:18; 43:8) and thereby to receive the divine mercy (Is 29:18, 35:5). Hearing disability is also used as an expression of moral insensibility. (Is 6:10, 29:18, 35:5; Ezek 12:2; Mt 13:15; Jn 12:40; Acts 28:26, 27).

Discrimination Against People With Physical Disability

In the Bible, physical disability is equated with inability. “Short hands”⁸ are not strong enough to save someone at the time of need. Yahweh is a deliverer because His hands are not short: “*Is my hand shortened, that it cannot redeem? Or have I no power to deliver?*” (Is 50:2b). The long stretched-out hand is of power unlike the “short hand” (Num 11:23, Is 59:1). Short hands are therefore inadequate and unable to accomplish any task. People with physical disabilities are considered physically weak. The Jebusites mocked David that their blind and the lame were sufficiently strong, to

⁸The Hebrew *q'fçr* means “short” or “shortened”. As an adjective, it occurs in the construct state in idioms: “short of hand”. This is translated as “feeble” in ASV or “of small power” in RSV.

frustrate his efforts to take Jerusalem, because of its strategic location (2 Sam 5:6, 8). In other words, its strategic location makes it possible for people with disability to ably protect the city and not their strength or skills. In response, David demeans the Jebusites by likening the whole ethnic group with the lame and the blind:

And David said on that day, “Whoever would smite the Jebusites, let him get up the water shaft to attack the lame and the blind, who are hated by David’s soul.” Therefore it is said, “The blind and the lame shall not come into the house.” (2 Sam 5:8).

People with physical disabilities were a despised lot. “Mephibosheth, the physically disabled son of Jonathan equated himself to a “dead dog.” *What is your servant, that you should look upon a dead dog such as I?*” (2 Sam 9:8). “A dead dog” is an expression of incomparable unworthiness of such distinguished favours. At the same, people with physical disability were seen as repugnant. David having Mephibosheth at his table would be probably out of pity and the indebtedness of his friendship with Jonathan⁹. Being physically disabled on both legs, he deserved to be treated unequally: “*So Mephibosheth ate at David’s table, like one of the king’s sons*” (2 Sam 9:11). Physically disabled people were also considered unfit for service in the Aaronic priesthood (Lev 21:18).

The stigma against people with physical disability is demonstrated in the comparison of the speech of the wise and the foolish. Like a physically disabled man’s legs, which hang ineffective, is a proverb in the mouth of fools (Ps 26:7). Such people have not skill to make a discreet use of it. The legs of the physically disabled are lifted up, in going, or in dancing, which is done with inequality. He shows his folly when he endeavours to talk wisely, just as the cripple displays his deformity when he tries to dance. His speech is not consistent, and his discourse “limps” like a cripple in walking.

⁹Josephus Ant., vii. 5, Section 5.

Discrimination Against the Left-Handed

In the scripture, the right hand is portrayed as superior to the left hand. An excellent illustration of this is in Gen 48:13-14 where Jacob blesses the two sons of Joseph. It is recorded that Jacob stretched out “his right hand and laid it on the head of Ephraim, who was younger, and his left hand on Manasseh’s head, crossing his hands, although Manasseh was the first born.” Joseph was displeased and tried to exchange Jacob’s hands, for there was already a significance attached to the right hand. Jacob refused to remove his right hand from the head of Ephraim.

Later Jacob explains that Manasseh also shall become a people and be great. However, Ephraim his younger brother shall be greater than he, and his descendants shall become a multitude of nations” (Gen 48:19)¹⁰. Blessings of favour and strength are transmitted through the right hand. God’s “right hand” denotes His omnipotence. “The right hand,” being more proficient than the left hand, is the place of honour (Ps 110:1; Mt 25:33), “the left” is the place of dishonour (Mt 26:64). Sometimes the right side is portrayed as the good alternative, and the left side as the evil one; thus read, “*A wise man’s heart is at his right hand; but a fool’s heart at his left.*” (Ecc 10:2).

Use of Derogatory Language

People with disabilities are not only discriminated against as individuals, but discriminatory language is also used against them in the bible. The Old Testament is most cruel on this. The concept of personal names in the Old Testament often included existence, character, and reputation (1 Sam 25:25). The name chosen for a child was often descriptive of the parent’s wishes or expectations about the personality that the child would have (Gen 35:10).

¹⁰Certainly probably out of Jacob’s blessing, in some biblical texts Mannaseh is subordinated to Ephraim in the genealogy (Num 1:10) and in the census conducted in the book of Numbers (Num 1:32-35).

Jonathan, King Saul's son had a son who was lame on both feet. His name was Mephibosheth (2 Sam 9:3). This personal name is derogatory and describes the nature and character of the bearer. His life is a series of disasters, disappointments, and anxieties (2 Sam 16: 1- 4, 19:24-30). The literal meaning of his name is "out of my mouth proceeds reproach". The last part of his name, *bosheth*, means, "to fall into disgrace". This dishonour is normally seen through failure"¹¹. In contrast to the primary meaning of the English words "to be ashamed," which stresses the inner attitude, a state of mind, in Hebrew, "to come to shame" stresses the sense of public disgrace, a physical state. It expresses a sense of confusion, embarrassment, and dismay when matters turn out contrary to one's expectations.

Caring for People with Disabilities

Despite the fact that people with different types of disabilities are discriminated against in the bible, the Israelites were admonished by the Law to show kindness to them. First, God does not forget people with disabilities. It is He who heals those with visual disability and restores sight (Ps 146:8). Second, the law forbids mistreatment of people with disability. The Israelites were cautioned to show kindness to those who were deaf and blind (Lev 19:14; Deut 27:18).

The community for example, was warned against putting a stumbling-block before those with visual disability or misleading them so that they wander out away (Deut 27:18). People with disabilities are to be treated kindly and offenses against them are regarded as breaches of Law (Lev 19:14; Deut 27:18). The spirit and letter of these laws was to ensure that no person would take advantage of people with different disabilities. These laws ensured people with disabilities were not injured or exploited. God therefore avenges for them. The Old Testament also gives an example that

¹¹See the context and other names such as Ishbosheth, "man of shame", (2 Sam 2-4) and Nabal "fool" (2 Sam 25:2). Me-fib'-o-sheth means "from the mouth of shame". That is, from the mouth of idols. In Chronicles he is called Merib-baal, "contender with Baal (1 Chr 8:33).

demonstrates that the healthy cared for people with disabilities. The nurse from whose hands Mephibosheth fell and broke his two feet, and other family members cared for him until he became an adult (2 Sam 4:4, 9:9). Israel was also called upon to honour the old. People who do not respect the old will perish (Is 3:5).

In the New Testament, Jesus welcomed people with all manner of disabilities into the Kingdom of God, even though they would have been excluded from service under the Old Testament law (Mt 4:23ff; 15:30). He instructed us on how to treat people with disabilities:

“Then Jesus said to his host, ‘When you give a luncheon or dinner, do not invite your friends, your brothers or relatives, or your rich neighbours; if you do, they may invite you back and so you will be repaid. But when you give a banquet, *invite the poor, the crippled, the lame, the blind, and you will be blessed.* Although they cannot repay you, you will be repaid at the resurrection of the righteous’” (Lk 14:12-14, italics mine).

Countless healings in the Old and New Testaments provide proof of the compassionate nature of God, in spite of the fact that not all illnesses, diseases, or disabilities were healed. Furthermore, people with disability were also subject to divine healing and treatment. Curing those with visual disability is one of our Lord’s most frequent miracles (Lk 7:21; Mt 9:27; Mk 8:23; Jn 5:3; 9:1). A few illustrations demonstrate this. In the town of Jericho, Jesus responded to the calls of Bartimaeus and healed him (Mt 20:30-34; Mk 10:46-52). At Bethsaida, he healed a blind man by spitting on his eyes (Mk 8:22-25). In John 9:1-7, Jesus heals a man who had been blind since birth (Jn 9:1-7). Jesus also healed people with speech disability (Mt 9:32, 33; 12:22; 15:30, 31; Mk 7:37; 9:17, 25, 26) and physical disabilities (Mt 11:5, 15:30, 31 21:14; Lk 7:22; 14:13).

Jesus Reinterprets Disabilities

The fundamental teaching of the Bible is love. However, the biblical text, especially the Old Testament views about people with different types of disabilities is inconsistent with this central teaching. People with disability are seen as flawed and hence not qualified to approach God. They were understood to pollute God's sanctuary (Lev 21:16-23). On the other hand, the teachings and examples given by Jesus persuade Christians not to discriminate against people with disabilities as it is taught in the Mosaic Law.

The New Testament also offers a different view about the relationship between God and people with disability. In view of the fact that, Christ came as a perfect sacrifice for all, the Old Testament prohibitions against people with disabilities are revoked. People with disabilities can therefore serve God in whatever area they choose (Rom 10:4).

During his life on earth, Jesus related with and restored to health people with disabilities. In these acts on healing, he demonstrated his power over the disability and discrimination noted above. Furthermore, Jesus also challenges the Old Testament belief that disability was always a divine judgment for sin. In John 9:2 he gives another dimension of disability. It is not always a sign of judgment. It could also be for the glory of God. For this reason therefore, not every disability can be healed. Similarly, Jesus did not heal all disabilities he encountered. At the pool of Bethesda in Jerusalem for example, he healed only one person although there were many with disabilities (Jn 5:1-11). Paul also teaches that people with disabilities are not worse sinners. Everyone has sinned and fallen short of the glory of God. It is with this new biblical interpretation and justification by Jesus, as written in the New Testament that I believe it behoves the church to initiate and support ministries for people with disabilities.

Disability, Society, and Theology

CHAPTER SEVEN

Lazarus, come out!

How Contextual Bible Study Can Empower the Disabled

Janet Lees

Introduction

This Chapter explores how people with disabilities (PWDs) can be empowered and integrated in the church and society through Contextual Bible Study (CBS). The chapter examines the CBS process and gives examples of how it can be used in worship and in bible study groups where people of all ages and abilities participate. The Chapter further discusses the contribution of CBS to the empowerment and inclusion of PWDs. It also gives examples of this process from ongoing work with people of all ages and abilities by the author in the United Kingdom (UK)

Jesus Reinterprets Disabilities

West et al (2007) define contextual bible study (CBS) as:

- a process of action and reflection;
- a bible based tool for social transformation based on community concerns;
- a process in which facilitators and participants work together respecting each others' knowledge and experience.

Other methods of CBS have been developed including the *Unlock method* and the *African Bible Study method* which may also be useful resources.¹

West (1999) argues that it is the retreating of biblical scholarship from the Christian community to the academy, which has resulted in it becoming remote from the lives of ordinary people. He advocates for CBS as a method of studying the bible that will bring together both ordinary people and socially engaged biblical scholars to work in partnership and interpret the bible together.

CBS is not one method but a range of ways of interpreting the bible according to context in which ordinary people and socially engaged biblical scholars practice interdependence as they interpret the bible together and discover each others' talents and abilities. According to Zarb (1992) accountability is a fundamental principle of participation. In tandem with the global disability movement, accountability means developing a process that amplifies the voices of PWDs based on their lived experiences. The system should be open and accountable to them.

Personal Experience

On my first visit to a church that had recently spent a large sum on improving accessibility for PWDs by installing a chair lift and new toilets, I was proudly shown these new facilities. Then, during the first part of the service, I asked for volunteers to help me with an activity for people of all ages and abilities. A nine year old disabled boy was amongst those who volunteered to help. 'He won't be able to do it, you know' said one of the older church members to me as the volunteers made their way to the front. 'Let's see, shall we', I replied. I explained the task and together the group of about half a dozen people began to find a way to do what I had asked. The boy joined in with the others, doing what he could, as enthusiastically as the rest. The whole group soon completed the task together.

¹These can be found at <http://www.unlock-urban.org.uk/resources.php> and <http://www.takomaparkpc.org/AfricanBibleStudy.html>

It seems likely that Jesus met many ‘He won’t be able to do it’ people during his life-time, both in respect of His own ministry and with regard to the role of PWDs in that society. One of the most disabling things about the contemporary church is the ‘He won’t be able to do it’ people. I could tell many stories of these limited folks and their deathly behaviour, just as I could give many examples of strategies for improving accessibility for PWDs like stair lifts, ramps, signs, toilets and large print books. Of course these strategies are important. However, what is fundamental to the inclusion of PWDs is how we interpret the bible together. That is why I have chosen to, through this Chapter; explore the potential of CBS as an answer. Empowerment and integration will be achieved only when we all appreciate the various perspectives from which the bible is interpreted. We should also ask ourselves: “How are our attitudes towards each other? Why does the church still harbour negative and limiting attitudes to marginalised members of our communities?” Through CBS, church members like one body of Christ can fundamentally challenge these dispositions and potentially transform societal thinking.

Link to Lazarus

The following comments on the character of Lazarus come from a bible study with people with learning and communication difficulties in Glasgow a few years ago (Lees 2007a, 2007b):

‘Mary said: My house is different. My brother is different. He lets me be different. He lets me learn and listen.’

‘He was useless and he went and died.’

‘I was not a well man. My name was never mentioned because I was never there.’

‘Lazarus said: I’ve not said a lot. My sisters keep the family on an even keel. I went and died. I’m a bloke with not many choices in life.’

‘I don’t think much was said about the brother.’

These participants revealed important insights about the part Lazarus, a silent man, played in the story:

Beginning of the story	Middle of the story	End of the story
Silence from and about Lazarus	Lazarus dies	Silence from and about Lazarus

People often assumed to be silent could identify with the huge silences in this story about the presence and role of a key character in the story; the silent Lazarus. As a result they emerged from silence alongside the character of the silent Lazarus.

The participants in that bible study are amongst the most marginalised in society. Furthermore, their contribution to the church is rarely valued. Indeed many church members see PWDs as unable to join in their preferred patterns of worship. Sometimes they even view them as disruptive. Interpreting the bible plays a key part in the life of the church at local and global levels. How we interpret the bible can empower some people and at the same time probably marginalise others.

Being Silent in the Church

People with speaking disabilities are amongst those marginalised in our verbal society, and our wordy churches. Speechlessness that accompanies some forms of disability, like cerebral palsy is not something we all understand. However, all of us do from time to time; know what it is to be ‘lost for words.’ We can therefore empathise with the silence of the ‘silenced ones’ who cannot talk. In our gospel that begins with the words ‘In the beginning was the Word . . .,’ too many interpreters use it to marginalise those with speech disability rather than liberate them. For the fluent interpreter in the wordy church speaking to the verbal society, Jesus as the central figure of the gospels is too often portrayed as one who comes to ‘restore speech to the speechless’ rather than challenge the injustice of the ongoing oppression of those who struggle in and out of silence.

There are passages in the gospels where Jesus Himself speaks little if at all. However, it is often his words that are the focus of

attention in the wordy church, not his silence, partly due to a mindset that sees silence as having less value and silent people as having less to contribute. As Vicki Terrell, a New Zealander with cerebral palsy has written:

‘I am aware of people enabling or disabling me through attitudes towards disability. At times people have encouraged me to do something I had thought impossible and I have succeeded. These people enable me to grow because of their support and challenge. Other times I have been limited by other people’s attitudes. When we disable each other we tend to have the attitude that we know what’s best for them!’²

The stories of Andrew, Paula, Leslie and Eric narrated below illustrate the thinking of society about people with speech disability. The following examples are taken from Lees (1997 & 2007c):

Andrew

Andrew has cerebral palsy. He uses a wheelchair for mobility and an electronic synthetic speech output device for communication. He is a full member of his local church. He goes there every Sunday and several times during the week to take part in the church’s activities. The church has a ramp on the outside of the building so that Andrew can get inside. However, once inside, Andrew’s full participation in the activities of this community is still not guaranteed. It is limited by the negative attitude of the other people he encounters there. In one of the encounters, Andrew was told by another member of the church; ‘Keep quiet in church. Do not play with your toy!’ The ‘toy’ referred to was his electronic communication device – literally his voice. Angry at this demand, Andrew was plainly and painfully ‘lost for words’ about the incident for several weeks. His

²Vicki Terrell (1999-2000: 73) quoted in *Justice, Joy and Jubilee*, the prayer handbook of the United Reformed Church (London: United Reformed Church).

anger persisted until he came across another person with speech disability who used a similar device. After programming the piece into his machine³, Andrew used it at the same church to describe how he felt after the bad treatment.

Paula, Leslie and Eric

Paula is the mother of a child with cerebral palsy. When she reads bible stories about how Jesus healed such children, she wonders why her daughter has not been healed. She thinks probably it is because she lacks faith. In the end, she blames herself for her daughter's condition.

Leslie is a paediatrician who has worked in the United Kingdom (UK) and in Africa for several years. He knows that different societies have different understandings of health and disability.

Eric has mental health problems. He enjoys reading the bible. But, just like Paula and Leslie, he feels that he has little to contribute to the process of interpreting the bible. Like many ordinary readers of the bible, these three people do not see themselves as experts.

Many ordinary people who have not experienced disability directly do not know much about the subject. In a recent survey by Horwath et al (2008), parents and young people were asked about their views concerning disability, religious beliefs and parenting practices. The findings indicated that having a child with disability in the family was one of the things that both groups found difficult to talk about. Majority of the parents of children with disabilities thought that faith was a resource for parenting. They also reported that they had seen discrimination and noted anti-disabled attitudes in their faith communities. Thus, they found it difficult to join or participate in communal activities. Young people did not of necessity know what

³In Britain, there is an increasingly wide range of 'voice output communication aids' (VOCA's) available. The one Andrew uses is called 'Liberator'.

the term ‘cerebral palsy’ meant. They also had limited access to information on disability other than what they got from family members.

The church’s tendency towards concentrating on ‘healing ministries’ rather than liberation, justice and empowerment of PWDs is also seen as negative and alienating by some disabled people (Lees 1997). Barnes (1991: 11) states that: ‘to pinpoint precisely the origins of society’s attitudes towards disability and PWDs would be almost impossible’. He examines psychological and economic theories that try to account for this but concludes that these fail to account for this widespread phenomenon. Advocating that cultural issues must also be considered, he states that ‘there is evidence of a consistent bias against disability and PWDs which has only recently been seriously challenged’ in our own society. The portrayal of PWDs has been ‘essentially distorted and inherently negative’. Such attitudes have rarely, if ever been challenged by church or society until relatively recently. It is not therefore surprising that a fellow church member might exhibit such a negative attitude towards Andrew’s participation in church life.

A Call to Action

PWDs are a minority in the UK society. More than thirty years since the formation of the global movement for PWDs, their voices are still trying to be heard in church and in society. In 2003, the World Council of Churches (WCC) published a statement ‘*A church of all and for all*’. This statement urged for progress towards a more inclusive church. Specifically, it advocates that ‘people with disabilities will be so valued, accorded equality with all, cared for in the community and not in institutions or on the margins of economically competitive societies.’

It also calls on the church to recognise that it is this central message of equality and dignity that it is called to promote in all of its work. As a place of hospitality and welcome, the activities of the church, including bible study, need to be open to all, without discrimination. Bible study needs to be a process in which all

members of the church can take part regardless of any impairment they may have in their actual bodies. In Britain, the increase in the ageing population of the mainstream churches means that more church members have sensory, mobility and memory impairments. However, few think of themselves as disabled. Furthermore, this impaired majority also fail to recognise the disabling attitudes that impede the participation of other PWDs, particularly those of families with children.

As a theologian with disability, Eiesland (1994: 70-71) critiques the 'Disabling Theology' which portrays the relationship between the PWD and God as 'either divinely blessed or damned.' This portrayal, she argues 'neither adequately represents the ordinary lives nor lived realities of most people with disabilities'. She traces both these themes to the bible and the way it has informed widespread cultural attitudes towards disability. Moral impurity and disability are frequently linked in the Hebrew Scriptures. For example, disability is used by the prophets to depict the disobedient people of God, who are, for instance, deaf to God's word. The link between sin and disability is still seen in the New Testament; something which Jesus is seen to challenge and sometimes accept and in different episodes. Eiesland (1994: 75) concludes that:

In order for the Christian church to stop doing harm and energise their efforts to be a body of justice, critical and careful attention must be given to a theology of disability as an established feature of the systematic theological enterprise. A theology of disability must be made a visible, integral and ordinary part of Christian life and our theological reflections on that life.

Unless this happens, she predicts:

The Christian church will continue to propagate a double-minded stance that holds up the disabled as objects of ministry and adulation for overcoming the very barriers that the church has helped to construct. Moreover, the church will squander the considerable theological and practical energies of persons with disabilities who,

like other minority groups, call the church to repentance and transformation. (*Ibid.*: 75)

In Christian liturgy, the association of sin with disability is still in common use. Whilst recognising that our churches are not living up to the standards of equality and welcome that are expected, we need to propose ways in which this can be achieved. We also need to offer examples of inclusive practice from which we can all learn. CBS is such a process that should be embraced by all.

People with Disabilities in the Bible

When people say to me that there ‘is not much about disability in the bible’, I wonder what bible they are reading. For me, the bible is full of experiences of people with disabilities. Perhaps I notice this since I read it with these communities in mind.

Even so, such people are on the edges of the bible which is written from a non-disabled view point with ‘being able bodied’ as its preferred cultural norm. The invitation to read the bible from the perspective of PWDs, including communication disorders must be undertaken with care. Carole Fontaine is a woman with disability who sees the bible as having much to say about disability. For her, ‘at least some of the theological ambivalence about those with disabilities’ is to be found within these texts.’⁴ Furthermore, Fontaine (1994: 111-112) states that:

The dignity of the disabled and their status as potentially valued members of their societies is directly challenged by the bible’s continuous portrayal of them as objects of divine action.

In her analysis, people with disabilities in bible texts, serve not as subjects but ‘marvellous plot-devices that show off the power of God or the Anointed One’ (*Ibid.*: 112). Her first strategy in re-creating

⁴Carole Fontaine (1994: 109) in Roundtable Discussion: Women with Disabilities, *Journal of Feminist Studies in Religion*, vol. 10 (2).

a ‘*Bible for Disabled Women*’ is ‘situating the voice of the marginalised as central rather than peripheral’ (*Ibid*: 113).

Applying CBS in Interpreting the Bible

Graham Philpott (1993), studying the bible with marginalised groups in *Jesus is Tricky and God is Undemocratic: the kin-dom of God in Amawoti* recognises the need to specifically include the perspective of PWDs in this piece of work from one South African base community. In their discussion of the ‘kin-dom of God’ the group uses an image of ‘new-life’. This image is taken from their communal bible studies and is described as follows:

‘We will see new life when:-
 people have a house;
 the disabled are accepted into community structures;
 there is a good relationship between the disabled of
 Amawoti and the Indians from Phoenix;
 the community is well organised;
 people are making a living by using their hands.
 We need to bring this new life (*Ibid*: 65).

CBS as advocated in this Chapter, is not so much about reading the bible for research but reading “with local communities as a resource for social development and transformation” (West 2004: 211). “We must learn to work together” said Campbell, advocating a shared creative process of biblical interpretation when he says: “we do not need calm solitude to approach a text, we need a clamour of diverse voices, a cacophony of competing insights, but with a real chance for the disparate whispering voices to be heard as well as the loud confident ones” (Campbell, 2003: 41). This is particularly important for PWDs who have long been silenced by church and society.

A CBS manual has been developed by West et al (2007). They describe approaches to interpretation using written biblical texts from behind the text, on the text or in front of the text. Interpreting the bible with PWDs including those with communication difficulties

using oral/aural remembered texts, has led to some practical considerations for those wanting to do similar work (Lees 1997). The considerations include the following steps:

- create a safe place;
- begin by using remembered texts;
- use an informed facilitator;
- encourage the repositioning of silent characters;
- make links between the many layers of silence.

A safe place is one in which people of all abilities are able to take the risks associated with working together. West (2004) agrees with the need for a safe space; one in which traditional power imbalances have been set aside and those most often marginalised are able to meet as equals with the elite and other more powerful groups. Facilitating such space requires careful consideration, training and evaluation. Participants with different impairments will require specific considerations to make the space ‘safe’. A fundamental question for facilitators will be ‘What adjustments and access arrangements need to be made so that PWDs can show off their talents optimally in the space provided?’

An informed facilitator uses the social model of disability⁵ and, where possible, works from it via their lived experiences. Toensing (2007) has corrected noted that we may not impose Western 21st Century understandings of well being on a text written in the 1st Century Mediterranean culture. Furthermore, Avalos et al (2007) argues that ordinary people and socially engaged biblical scholars need the insights and research developed by those doing biblical studies from a disability perspective to inform their understanding of the social and cultural history of the bible.

Toensing (*Ibid*) concludes that the process of interpretation is a complex one and has many different facets. Describing these

⁵The Social Model of Disability is that advocated by disabled people themselves and recognises that it is society itself that views impairments as handicaps as seen in its structures, use of resources and attitudes.

facets is part of the process of developing critical interpretation skills for ordinary biblical interpreters. Silent and often anonymous characters at the edges of the texts are often good places to begin to see the text from the perspective of people with communication difficulties and disabilities. Interpreting the bible with people with disabilities has shown that their interpretation involves many layers of silence: historical, cultural, sociological and ideological. Resources like those presented by Avalos et al (2007) can help to uncover these facets.

Remembered Bible as Key to CBS

‘Biblical texts are living traditions that are challenged and renewed by lived experiences of ongoing generations of Christians’ (Toenisng, 2007). But what bible shall we use; those of us who cannot speak, read or turn over the pages?

We will use the authentic bible of the people: a remembered bible. Bible study participants with communication impairments say they use remembered versions of the bible rather than written ones. Robin, a professed religious woman who has dyslexia, said ‘From my point of view, the bible stories come alive when they’re told’ and ‘If it’s read in chapel it goes right over my head. I don’t really hear it’. Furthermore ‘It’s more in my body, in my heart, in my gut, than in my head’ (quoted in Lees 1997:79-82).

Remembered versions of the bible are used by many people, including those with communication difficulties and disabilities. West (1999: 96) states that “ordinary African interpreters work with a remembered as well as a read bible.” He reviews the work of a number of African biblical scholars on this issue and concludes that remembering the bible is “a communal process” in which the read bible and the remembered version “reside side by side” (*Ibid*: 96). Limited literacy and communication impairments will influence the way people interact with the bible. An oral method of using the bible means that remembering and interpreting the text occur together because our interpretation probably affects what we remember as much as the content of what we remember influences our

interpretation.⁶ Putting the process of remembering and interpreting into the hands of ordinary people, including those with disabilities like communication difficulties, will open up the potential for a whole new range of public understandings of the bible.

Trained readers may have to put written texts aside sometimes and be prepared to use the remembered versions of ordinary people when working together. Using remembered texts does not preclude also working with written texts as the two can be used side by side, as West (1999) has indicated. However, using remembered texts may be the only method available to some disabled participants and should be equally valued. After all, it is the remembered bible that is in us all.

I have described a range of methods of using remembered bibles with people of all ages and abilities from work carried out in the UK for over a decade, described as “a critical pedagogy of the oppressed” in the Freirian tradition (Lees 2007a, 2007b). It is not claimed that this CBS method is unique, or that it is ‘cast in stone’. Rather, it is an experimental method which people have found to be inclusive and empowering (Lees, 2007, a,b,c).

Conclusions

Avalos et al (2007: 200) concluded that ‘the bible has had a prominent role historically in shaping readers’ attitudes’ to which I would also add the attitudes of ‘rememberers’ and ‘retellers’ of the bible as well. Whilst disability studies ‘is first and foremost about people and how we value them’ (*Ibid*: 197), the place where CBS and disability studies meet will share in a common ‘concern to improve conditions for living persons’ (*Ibid*: 200). When the silent Lazarus comes out of the tomb still swathed in bandages, Jesus instructs the assembled community to unbind him. The liberation of Lazarus and of us all is a shared, communal responsibility. It is to that end that I commend

⁶Note that nonverbal methods of communication such as symbols, pictures, mime and drama can also be used in contextual bible studies of this kind.

the process of contextual bible study for consideration, adoption and development by the Ecumenical Disability Advocates Network (EDAN) as both a tool and strategy as we work together for the further inclusion and empowerment of disabled people.

CHAPTER EIGHT

The Church, Public Policy and Disability Concerns in Kenya

Phitalis Were Masakhwe

Introduction

People with disabilities (PWDs) have been shunned and subjected to various injustices by society for years all around the world. Some have been killed, abandoned, forced to beg on the streets or thought of as less than human. The reason for this maltreatment in countries like Kenya is the many misconceptions and myths about the cause of disability. Unfortunately, many of the myths emanate from religious traditions. Many people believe that disability is a curse brought by witchcraft or God. Others assume that someone with a disability cannot contribute anything to society.

Legislation and financial assistance is not enough to dramatically change this perception and hence, the lives of PWDs. Deliberate efforts must be made to change the mindset of the community. Many will ask: 'How can mentalities be changed? The answer lies in starting the campaign with the group of people who have been intimately engaged and involved with PWDs in the community for years...the church.'

In many Kenyan communities, people emulate the clergy and pastors as the mirror of society. In some incidences their word is law! Therefore, if all religious leaders despise PWDs, the community

at large will do likewise. However, if pastors acknowledge that the bible calls upon them to meet the needs of **all** people; they can help preach this message to those in their communities. The result will be positive change in people's attitude towards those who have special needs or those who 'look different' in their own communities.

Personal Experience with the Church

My own personal experience with the church has overtime been both positive and negative. Growing up in Matawa village I enjoyed Sunday services in either the Anglican or Catholic Church. I especially liked the choir and the powerfully delivered sermons by the clergy. I chose to attend either of these churches because they were near. Despite my physical condition, I could easily walk there whether or not I had a means of transport.

On the negative side, every time I went to church, I always felt humiliated. The "lookings" I was subjected to by fellow worshippers while making my way in were very disgusting. Almost everybody made me wonder whether there was something "wrong" with me. Many a times the preacher would change the prepared sermon and instead wander off to the subject of disability. Jesus' command to the disabled man who was told to take up his mat and walk was a particularly favourite of this preacher (John 5:8)

Later in life, my first conscious encounter with the church was in the year 1995 while studying at Mombasa Secondary School for the physically handicapped. T L Osborn, a leading evangelist, so they said, came to Mombasa for a healing crusade. The school's administration in their wisdom, choose to pack us (students) in the school bus and take us to the Mombasa municipal stadium so that we could be prayed for and supposedly be cured or healed. Monday to Friday every day, we were religiously taken to the stadium and positioned near the dais where T L Osborne was preaching from. Curiously, none of the teachers in the school would accompany us. Only the school driver shuttled us to and from the school. In the end, none of us was "healed" as expected! Back in school, we later

overheard some teachers say that we could not be ‘healed’ because we had no “faith” whatever that meant.

The second unfortunate experience happened one day at our family house in Kakamega while I was having lunch with my wife and children. Suddenly, a radio announcement was made in Kiswahili urging all “the cripples, blind and deaf” to go to Nyayo stadium in Nairobi for a miracle healing crusade. My eldest son Nelson looked at me and said; ‘Daddy, what are these people saying –, that you should go for healing? You mean you are not well?’ I did not know how to respond to my child who was obviously inquisitive about the announcement by a “leading” evangelist R Bonke, who was visiting Kenya on a ‘healing’ mission.

The Church and the Disabled, A Historical Perspective

In one of his most read books, “*Church and Politics in East Africa*”, the late Kenyan Bishop, Dr. John Henry Okullu describes the church as the conscience or moral compass of the nation. The church’s stand on anything is taken very seriously by its faithful. Also, its position on any public policy attracts near fanatical following. It is therefore important that the church’s stand on the place, role, rights and dignity of PWDs be made unequivocally clear. Any ambiguities and ambivalence as has been witnessed in the past can greatly damage public perception on disability and hence the image and dignity of those born with various forms of impairments.

Talking about image and dignity should remind us of the creation stories. The bible says that **all** of us were created in the image and likeness of God! The **all** is a categorical encompassing statement. It means that even those with disability were also made from the same image and likeness of the same God! It does not say that those with disabilities were made from the image of a monkey or anything else! It therefore logically follows that, one of the images, likeness and characteristics of God is that of disability. Any person, therefore, whether clergy or otherwise that demeans persons with any form of impairment is actually defacing and defaming the image

and likeness of God, for that is where those with disabilities, came from!

Jesus Himself the son of God was confronted with this issue about why disabled persons were born and who was responsible for their supposed calamity? “Neither his parents nor himself are responsible,” He said. He said that the man in question was disabled so that God’s glory can be seen.

But, in the same holy book Jesus himself and his disciples are seen exorcising demons and performing miracles to heal PWDs. This means that they “lacked something”, they were not complete, and that PWDs possessed demons – strange beings.

The same bible several times refers to persons with disabilities as those with blemish or flawed beings. As a matter of fact, no such people were allowed to be priests! No wonder there are very few clergymen and women who are disabled! So, stigma and discrimination and the feeling among majority of the clergy that persons with special needs have to be prayed for, be “healed” and be “restored” as is tradition in the holy book. If their holy book and their own master Jesus Christ subscribed to this disabling and disturbing perspective into disability, who is the ordinary follower to defy them? Defiance here could mean ‘earning one a free ticket to hell.

But even with all these ignorance and confusion about PWDs, the church either due to a sense of guilt or otherwise was a pioneer in some of the great initiatives that have overtime led to gradual empowerment and recognition of PWDs.

The Church and the Disabled, A Historical Perspective

The Catholic Church’s public stand against abortion should be applauded because it has safeguarded the birth and raising of many children with disabilities. Otherwise, contemporary scientific, medical research and experimentation would have been declared such babies unwanted and eventually killed.

Much rehabilitation, educational, economic empowerment programmes that have given succour to persons with disabilities

were initiated by the early missionaries. Though some of the programmes were started as “homes” and may have largely been informed by mercy and sympathy to do good, many disabled persons (myself included) scrapped through these institutions to reclaim our sense of self worth and dignity. The education we got from these institutions will forever remain our light, shield and defender.

The church must therefore do more than just building institutions for the disabled. It should be more rights-based, holistic and adopt a developmental understanding and appreciation of disability. Although the church has been strong on the “bread and butter issues” of persons with disabilities, the church remains a reluctant reformer with regard to individual rights, development and governance concerns of persons with disabilities.

The church has been very vocal on the rights and against marginalisation of women, children, migrant workers, refugees and other interest groups. It has also added its voice to environmental conservation and other related issues. Sadly, the church has not been very vocal in defending the dignity and rights of PWDs. It has not come out strongly to demand the inclusion and effective participation by persons with disabilities in socio-economic and political activities.

Occasionally, the church in Kenya has issued hard hitting Episcopal letters touching on democracy, human rights, good governance and other perceived social injustices. Not once has it deemed it necessary to denounce political marginalisation of fellow citizens who just happen to have disabilities.

However, we cannot conclude that all is lost. The church like any other institution has been undergoing a lot of reflection and soul searching on the issue of disability and disabled persons. It is gradually, though belatedly recognising that disability is indeed part and parcel of the diversity inherent in humanity.

In the Catholic social vision, the human person is central, the clearest reflection of God among us. Each person possesses a basic dignity that comes from God, not from any human quality or

accomplishment, not from race or gender, age or economic status. The test of every institution or policy is whether it enhances or threatens human life and human dignity. We believe people are more important than things.

The ministry calls upon us to reach out to those who are suffering and are in need of safety. It requires of us to compassionately engage and respond to those who are in life threatening situations. This we can do by initiating educational programmes and providing resources so as to enhance the lives of people with special needs.

In our relationship with PWDs, we should always understand and be guided by the sanctity of human life. Each and every person has a right to life – irrespective of his physical state or condition – whether disabled or not. We must obey the commandment – ‘Do not kill.’ The bible can be useful in influencing the ‘public disability policy’ since it specifies the actions which should be, and which should not be carried out.

Therefore, the urgent need for church to participate in championing disability concerns cannot be gainsaid. The clergy should lead other worshipers in interacting more closely with PWDs. Once PWDs are able to trust the general public, they (PWDs) will be able to express themselves more freely knowing that they are appreciated the way they are.

Public Policy

Making public policy requires us to think about problems that are of general concern to the public and then find solutions. The solutions are then formulated into a policy and law that is obeyed by all in the community. A good disability policy should include those laws specifically targeted at addressing the needs of persons with disabilities and their families. It should also address generic laws that address the needs of non-disabled persons as well as persons with disabilities.

It is also mandatory that PWDs should be involved in the policy-making process as disability policy change agents. This will ensure

that our laws foster the inclusion, independence and empowerment of PWDs and their families.

Passion, anger, frustration and commitment are often necessary but not sufficient characteristics of a disability policy change agent. In order to formulate and advance a progressive disability policy, an effective disability policy change agent must channel those emotions and beliefs and develop the skills and understanding among the rank and file of the Christian community.

The Way Forward: Some Reflections

Public Awareness

Change of attitude has happened in areas where pastors have been encouraged to discuss the issue of disability openly in their churches. For example, *Kupenda for the Children*, a local non-governmental organisation (NGO) in Malindi, Kenya that champions the plight of PWDs sponsored a pastors' workshop where they learnt about disability. One of the successes was, a child who was deaf and had been kept at home for long was enrolled in a special needs school for rehabilitation and education. How did this happen? A pastor who attended the workshop went home to tell his congregation how PWDs amidst them should be valued and that they had the ability to learn, just like anyone else. A member of the congregation had proceeded to inform a neighbour, who happened to be the father of the child.

Therefore, if every church took the responsibility of educating their communities about the value of people with special needs, increased awareness could mean more receptiveness. Consequently, public policy as we know it would tremendously change for the better. Ultimately, there would be dramatic life improvement for people with disability.

Accessibility to the Word of God

The church should provide resources that will enable people with disabilities to fully access and participate in church activities. Access involves provision of large-print prayer books, sign interpretation at

services and training for children with special needs. It should also include increased sensitivity to the scope of needs within each community – to encourage the congregation to copy this practice and replicate it elsewhere. In addition, the clergy should teach congregations about the needs of PWDS and engage them and members of their communities in formulating strategies that can help remove barriers.

Attitude Change

The general population and especially the church should change their attitude towards PWDs. They should view a PWD like any other normal person. The churches should accept barriers that exist in society today and make deliberate steps to correct the anomaly. One method is by using a network of volunteers to raise public awareness campaigns. The church can also educate the public through periodical newsletters, a website or through meetings and regular consultations in church

Role of NGOs

The aim of *The Episcopal Disability Network* is to enable each child of God, regardless of the severity of his or her disability, to be an integral member of the Body of Christ, to participate in the sacraments of the church, and to discern and live out his or her calling as a Christian. To this extent, it has been very helpful in addressing the concerns of PWDs. This is because; *People with disabilities and their families have gifts, talents and abilities to offer the community of believers as full participants. They desire to exercise their leadership abilities, both to give and receive in relationship with others! They thus need to be integrated in society.*

Another NGO I will discuss is *The National Catholic Partnership on Disability* (NCPD). NCPD was established in 1982 to foster implementation of the “*Pastoral Statement of U.S. Catholic Bishops on People with Disabilities.*” Passed unanimously on 16 November 1978, this prophetic document calls

for the welcoming to church of over 14 million Catholics who live with disabilities. It states that these persons must be able to participate in the celebrations and obligations of their faith. The statement also advocates for their inclusion within the total fabric of society.

Church Members

Church members should also recommend possible actions that can make the church facilities more accessible to PWDs. Members can also assist the church in providing transport to PWDs. They can also freely advise the church leadership on how PWDs can be involved in church activities

Conclusion

Therefore, all local churches should pay special attention to all their members and especially those with disabilities. The church should give PWDs opportunities to witness and also arrange programmes for them to be witnessed to.

On the other hand, it is important to formulate a policy on disability as argued above. A new policy on disability should focus on the following:

- Recognise the goals of disability policy, that is, equal opportunity, full participation, independent living and economic self-sufficiency.
- Equal of opportunity – individualisation, inclusion and meaningful opportunity.
- Full participation – empowerment at socio-economic and political spheres, self-determination and informed choice at individual and systems level.
- Independent living – skills, services and supports.
- Training, education, assistance and supports.

Disability, Society, and Theology

CHAPTER NINE

Cultural Barriers to the Disabled People's Participation in Church Life

Reuben Kigame

Overview

This Chapter will define the subject, state the problem and discuss the current response by the Church to barriers that PWDs face. It will show some of the reasons why PWDs are locked out of Church life. The Chapter will not follow the strict formats required by academicians. Instead, it will give a layman's perspective on the subject. I have avoided library research and chosen to use my own experiences and those of the persons I have held discussions with on the subject. For purposes of confidentiality, I have not made any explicit reference to them, except those closely related to me and whose permission I sought. References from the Bible are taken from the New International Version (NIV).

The chapter will not examine individual barriers to all the persons living with disability. It will instead focus on a few case studies of PWDS ranging from the hearing impaired, physically impaired, visually impaired and the speech impaired. More follow-up comprehensive studies can be done on each of these case studies or even be extended beyond scope of this Chapter. Recommendations shall then be made with a view to reversing the

evident negative trends in the Kenyan Church which entrench these barriers.

Definitions

Disability is defined as the impairment or minimisation of one's body or mind to levels significant enough to limit or hamper one's normal participation in the regular activities of life. A person living with disability may as well be able to overcome such limitations through the acquisition and use of supportive equipment. Those who are not disabled can also provide opportunities for PWDs to alleviate the challenges PWDs face. However, the fact that PWDs need supportive equipment or opportunity illustrates what we mean by disability.

Cultural Barriers refer to beliefs, attitudes and practices of the society which, having become the norm, contribute to the limitation of the normal life of PWDs. When such beliefs, attitudes and practices define the way people in any given community relate to PWDs, this could be summed up as part of a people's culture. Although this Chapter uses "cultural barriers" as seen in the context of Kenya, reports from other parts of Africa confirm that many similarities exist from among the various communities.

Participation in Church life is viewed as a standard way of living expected of anyone with faith in Christ and the Bible and is guided by what the Scriptures say. Church life is therefore seen as being all-inclusive. It encompasses among others, job and career matters, family life and responsibilities, the role in fellowship activities such as singing, praying, The Lord's Table, preaching and evangelism. The "church" in this case refers to the "Early Christians" understanding: a community of people who are united by the love, death and crucifixion of Jesus. They serve Him and exercise love for humanity as they anticipate His imminent return (Acts 2:42-47).

Statement of the Problem

Although we constantly use phrases in our communication which suggest that we are all equal under the law and under God, George

Orwell's statement in *Animal Farm* to the effect that "some animals are more equal than others" still gnaws at the foundations of our society. People living with disability continue to experience barriers to normalcy at home, at work, in educational institutions and, worst of all, in the Church. Since Church members are part and parcel of the wider culture, they carry over cultural attitudes, beliefs and practices into the church. These customs and culture continue to entrench discrimination and maltreatment of people living with disability, while church members profess to love God and fellow man without fear of contradiction.

While those outside the Church are equally to blame, those within the Church have a greater duty and responsibility to work towards removing these barriers. This Chapter seeks to digest this problem and make it clearer so that the church can understand it, own it and use the recommendations to remove the cultural barriers that exist in society. This summary perspective will equip the Church to be able to deal with the issue of exclusion of people living with disability within her domain.

The chapter also provokes further thinking on this matter and encourages an in-depth analysis by other stakeholders. Following is a discussion on the microcosmic representation of barriers among four main groups of people living with disability and how the Church may minister to them so as to remove the barriers.

Barriers Affecting the Hearing Impaired

Back in 1995, my music team and I were invited for a music ministry and to share God's word with students of Kerugoya School for the Deaf in Kenya. As we drove from Nairobi, many questions kept popping on my mind: "How will they hear, let alone enjoy our music (the keyboard tracks, my guitar playing and the harmonious voices of the team)? How exactly will we get them to hear and "truly" understand our preaching? How will we converse with them and they with us?" We had committed ourselves to spend the whole weekend with the students.

What transpired over that weekend nullified all the doubts and feelings of indifference. At the end of it all, I had to repent because of my earlier misgivings and the sheer apathy towards the world “my comrades in disability” lived in. That weekend, I discovered the beauty of the sign language, the skill of enjoying music without the outward ear and the hearty appreciation of the ministry, not to mention the shock I got when several students responded to my message by publicly making a commitment to follow Jesus!

Everything about that outreach was interesting to all of us. It particularly opened my eyes to several barriers the hearing impaired face when they go outside their immediate environment, including unnecessary barriers to corporate worship. My previously blind eyes were opened wide to the realisation that the Church had failed to effectively address at least three main barriers to the participation of the hearing impaired in normal Church life as discussed below.

Stereotyping

As is the case with many other handicaps, the Church often makes the same mistake the world makes by promoting disinterest in and the stereotyping people with hearing disability. In a charismatic fellowship, the pastor shouts his undirected communication to a member of his congregation, perhaps believing that the deaf person is incapable of sensing the detached communication. Another commands parents of a young deaf girl to bring her to the altar for exorcism, believing that every manifestation of deafness is a sign of demon possession.

As with other disabilities, the hearing impaired are often viewed as springing from a cursed family. Numerous Church ministers assume that the deaf are incapable of understanding anything and that the verbalisation of their thoughts through what nobody seems to want to study, is mere meaningless babblings. Sadly, you might then find such ministers of the Gospel gently rubbing a cat's or dog's body and responding affectionately and patiently to the real babblings of the pets. While I do not desire to be disrespectful to those who dearly cherish their pets, Jesus taught that humans are of

greater worth than all of flora and fauna (Mt 6:25-34). In paying more attention to “fauna” (the pets, poultry and livestock) and flora (perhaps as typified by the love of nature), I am persuaded that Jesus’ teachings in this passage is reversed when it comes to dealing with PWDs.

Socialisation

Without a doubt, many a Church minister and Church member will spend less time with PWDs but accord more time and attention to ‘normal persons.’ They will invite ‘normal persons’ to their homes, suggest lunch or breakfast dates, play tennis, basketball or a game of cards with them. This is strange, because they will rarely invite a PWD even though many a handicapped person could be better players. Although the hearing impaired can be involved in social activities in the Church, just like other members, they are hardly given such opportunities due to stereotyping. Through many parables and remarks, Jesus reminded her bride, the Church that this ought not to be so.

Lack of Knowledge on Available Communication Channels

The Church has failed to use ministry opportunities to reach or involve persons with hearing disability by applying communication channels that are suitable to them. She therefore remains increasingly unwilling to incorporate PWDs in Church life. We can only conclude that it is the lack of knowledge about the available channels of communication like sign language, even though society is very conscious of their existence.

An average pastor or evangelist may not know what a *hearing aid* is. Your bishop or priest may not have heard of *sign language*. Find out from your local church whether the pastor is familiar with these modes of communicating with people who have hearing impairment. If not, stop wondering why we are not making progress in reaching this important segment of the congregation. Is it then any surprising that we are moving very slowly in integrating our hearing impaired in Church life?

Not taking interest in the affairs of the hearing impaired by the clergy is not just unchristian. Here, the church fails to rise to the occasion and make a difference in the lives of PWDs, however few in any given congregation. What a blessing it would be if sign language was adopted in Church services! The hearing impaired would be able to enjoy songs, testimonies, sermons, Church announcements, etc., just like any other member in the congregation. Only a word from the pulpit is what is required for members of the church to take interest and learn how to communicate using this means. This would enrich the culture of the Church and in effect make it more inclusive. This way, the Gospel of the Kingdom will be preached to everyone until the end comes (Mt 24).

Unhealthy Beliefs About the Hearing Impaired

Just like in the case of other PWDs, the church believes that hearing impairment is a result of what is labelled a “generational curse.” This belief has been popularised by the teachings of Derek Prince in his book, *Blessings or Curse: You Can Choose*, Church handouts and other publications. The paradox is that, when the community labels and isolates the deaf person, he or she feels shunned by the Body of Christ which at the same time preaches the need to love everyone.

Some Churches treat the hearing impaired with disdain because they believe the disability is a result of sin. Others will go further and attribute the disability to lack of sufficient faith to procure “miracle” of healing. These thoughts and beliefs result from a bad hermeneutic or simply bad theology. Sending Church ministers to theological schools is not enough to change their mentality. Theology schools as a matter of urgency need to introduce studies in disability and integration so as to educate the masses about relating with PWDs.

Barriers Affecting the Physically Impaired

During one Sunday service at a Nairobi congregation many members of the Church were shocked to see that people with various handicaps were “in charge” of the service. This was a special service organised

by the Church to launch a disabled person's ministry. PWDs were assigned all roles right from the call to worship to the preaching. The speaker was a Minister of the Gospel with physical disability. He had to preach from the top of a table specially set up for him. I believe God used these wonderful brethren in a unique way. Although many people learned a lesson from this inclusion, others probably thought that the regular service had been seriously interrupted. Most likely, they might have wished that this special service should not have departed from the usual routine. Perhaps they thought that this was not up-to-date with the practice of normal worship.

The reluctance by certain bible colleges to admit PWDs is evidence of serious latent attitudes by the clergy. It is unfortunate that many still hold the view that integrating PWDs is far from being realisation. While congregations like the one cited above are to be commended for involving PWDs in their services, albeit once, others need to be castigated for practicing a Christianity of exclusiveness. Below are some common barriers experienced by the physically impaired in Church integration.

Presumed Needs-Based Exclusion

The term physical disability is used here to mean involving the body as distinguished from the mind or spirit. An informant once told me that the physically impaired are easily identifiable compared to other people living with disability. "You would have to try and talk to a deaf person and receive no response to really know that they are deaf! But, the physically disabled will be easily spotted in a congregation, and hence assumed to have a special need," she said. Naturally, many Church members will shun such persons in order to avoid presumed dependency. Even well educated and resourceful physically disabled persons who could contribute to the growth of the Church are ignored for this reason. Such congregations end up missing out on what could have been the solution to many of her challenges, just because of attitude.

By the same indication, many physically disabled persons develop coldness to the Church, its membership and institutions

because of such attitudes. In fact others end up losing their faith in God altogether. The Church leadership needs to be reminded of Jesus' words that whoever causes any of His servants to stumble faces the wrath of God (Mt 18:6). In these sobering words, Jesus states that: "But if anyone causes one of these little ones who believe in me to sin, it would be better for him to have a large millstone hung around his neck and to be drowned in the depths of the sea."

Excluding physically impaired persons from Church life because we think they cannot act independently amounts to maltreatment. By so doing, we deny them even genuine human needs that have nothing to do with their disability. Avoiding PWDs makes it difficult for them to even express their desires. For instance, a physically impaired person has just been dropped at a Church by a friend. If we do not talk to him or her, how does he find his or her way to the toilet? How will he reach the altar? I guess he or she will even require extra help to reach the pulpit. If such help is not readily available at the Church, who should PWDs turn to?

Mobility Hazards

In 2003, I was invited to minister at a National Day of Prayer and a Protecting Life Movement rally, both of which were held at Uhuru Park in Nairobi. As I was being helped onto the platform, I noticed that the stair was very steep. It was so high that as I ascended, a question popped up in my mind. "If this is so hard for me, how about my "comrades in disability" who may need to drive a wheel chair onto the platform or use crutches to go up that stair?" I asked myself. Then, my mind drifted to the numerous storey buildings around our country. Many have no lifts and, the escalators are so narrow and cumbersome that PWDs cannot easily use their mobility aids to move around freely. In addition, not many Churches have a ramp that leads to the Church Hall. Besides, when such provisions are made, they are not accomplished professionally. Therefore, having a ramp and such like devices is not enough. Architectures have to be impressed upon to make proper ramps and just shoddy jobs that are intended to please and show conformity.

Although there are many gifted PWDs, it is very rare for the Church to integrate them in activities such as singing in the Choir, distributing the Church bulletin which some can do comfortably from their wheel chairs, or even preaching with a table as an elevation. Perhaps, some think it is not so good a sight; that is a manifestation of the absence of 'miracle' healing in the particular Church.

We are all called upon to be alive to responsible architectural planning so that PWDs can easily access Church buildings. This is, and should be not only a calling, but a duty for each and every Shepherd of the Church. We can achieve this even more aptly by consulting with PWDs when putting up buildings. Access to the church and its facilities, like the office of the pastor, washrooms and pulpit should not be taken for granted. We should not allow the same stereotypes about PWDs to continue.

Social Obstacles

One of the most discouraging situations I have observed in Church is when a person in the congregation is interested in marrying or employing a physically impaired person. Most pastors or Church leaders will ask the person interested very leading questions. Such questions, no doubt cast doubt in the mind of the interested person. There seems to be a constant worldly perspective within the Church that encourages existing cultural notions to the effect that such socialisation is a reserve of those who are not impaired in any way.

We were a little surprised when the Ministers at a Nairobi Church where we wedded accepted our bridal train the way it was! Why do I say so? You know, a relative of ours who uses a wheel chair was part of the bridal team. She was going to 'walk' down the aisle in her wheel chair. The decision by my would-be wife to include this lovely sister in her 'train' endeared me greatly to her. I was most delighted because my wife and I used this great opportunity to 'shout' to the huge crowd that witnessed our wedding that it is possible. This gesture ought to be the norm and not the exception. It happened that this same relative had been one of the most resourceful persons when we were planning the wedding. Her clear perspectives

and deep insights into some issues saved us from overspending in several key areas. Is it not a pity that the Church does exclude such persons from key leadership roles!

Barriers Affecting the Visually Impaired

From time immemorial, blindness has been viewed as one of the worst conditions of disability. It is a prominent theme in movies and certainly, one of the top handicaps that attract many a televangelist in the quest for the manifestation of supernatural power in meetings.

One early morning, we were on a mission trip with several Christian friends. Suddenly, one of them requested me to accompany him to a morning prayer in a bush. Once in the bush, we started praying as usual. Nothing prepared me for what happened next. Just as we were nearing the climax of our prayer, he started shouting: "I believe God wants you to see again! ... I want to pray for you ..." This he did as if some celestial seizure had happened upon him.

I tried to persuade him that, just like Paul, God's grace was sufficient for me. No amount of my persuasion would deter him from his mission. Just like several others who had approached me with the same conviction, I suppose, he also concluded that I did not have enough faith. That is why, in his opinion, I remained blind.

As if that was not enough, much more was on the way. Many years later, I sent to the pastorate a circular letter warning the Church about some destructive doctrine as taught by a televangelist. This televangelist was about to visit our country, Kenya. What followed was not unexpected. I received several strands of communication. In many words, they told me what I had experienced before – that I was blind because of disbelief. They vehemently beseeched me to repent for misleading the Church and turn to the coming "man of God" so that I can see again.

We have already seen that this belief is rooted in the Old Testament and goes back in time. Even in the days of Jesus, the blind were looked upon as being at the fringe of society, fit only to sit by the roadside and beg. We read in John 9 the same kind of attitudes in the days of Jesus as is common in many African societies.

“As He went along, He saw a man blind from birth. His disciples asked Him, “Rabbi,” Who sinned, this man or his parents, that he was born blind?” “Neither this man nor his parents sinned,” said Jesus, “But this happened so that the work of God might be displayed in his life. ...”

Cultural Barriers

There are three main barriers that the Church has set before her visually impaired members: communication, misplaced concern and mobility. These are discussed under the given sub-headings.

Communication Barriers

Many churches have embraced advancements technology. Nowadays, it is common to see members sing from huge monitors that magnify power-point-prepared lyrics. The normal hymnbooks are no longer cherished. Indeed, modern churches are very proud of such technologies.

However, no one seems to think about the blind. No attempt is made even to provide Braille song sheets. I have been involved in assisting many worship teams. Nevertheless, I do not remember any one moment when a Church leader tried to facilitate my involvement in such leadership by offering an alternative. No one even cared to know how I as a blind person could use the song sheets and the overhead transparencies that everybody else was using.

Similarly, although the British and Foreign Bible Society and several American Bible associations willingly give Braille Bibles to anyone in need, I do not remember any Church I have regularly attended or visited possessing a copy of the Bible in Braille. Note that the above societies offer these Bibles at no cost and just about any transport service or postal group will gladly ship Braille material for free. Church libraries do not stock Christian literature in Braille and very few Churches will have a lending service even for the audio messages preached in the services. The messages are often sold for revenue. A lot could be done to reverse this situation.

Another aspect of communication that acts as a barrier to Church inclusion for the visually impaired is the regular use of insensitive language by Ministers in preaching. Common examples will include statements like, "You cannot be as careless as that unless you are like a blind man who walks into walls because he cannot see!" or, "Do not be like a blind man who does not know where he or she is going!" or the common expression, "Love is blind" when used to justify wrong relationships. Some visually impaired persons have abandoned fellowships because of this unkind and inferior use of linguistic references to their state. During one of my visits with my fiancé to a mutual pastor friend who would play a role at our wedding, I pulled out the vows we had written to each other so that he would have an idea of what was going to be different about the vows. After looking at my fiancé's briefer vows, he read mine. They were several sentences longer. Perhaps without thinking about it, he made the comment, "Those who say many things usually have something they are trying to prove!" He then proceeded to explain that the briefer the vows, the more sincere. With an attack on the only means I knew to show my wife-to-be that I was totally committed to her, I certainly found it difficult to listen to the rest of the bits of advice he had for us that day. What he did not know is that words mean a lot more to me than ten pictures.

Misplaced Concern

Imagine the following; a visually impaired person walks into a pastor's office together with his wife who is six months pregnant. There is only one seat for visitors. What do you think will happen? No doubt, both the pastor and the man's wife will expect the person with visual impairment to sit. Not only that but, they would both protest his decision to leave the seat for his wife. This will happen even if the visually disabled person insisted on standing and letting his wife to sit. This happens more often than not. Why is this so?

First, there is the secular attitude that unqualified sympathy should be accorded to the blind at all times. This has not escaped the Body of Christ. Both the pastor and the man's wife would probably

feel they were being unkind if they let him stand and his pregnant wife sit.

Second, there seems to be a latent belief that if you are blind, you need to be treated gently and given all the privileges including absurd ones like the one cited above. Blindness is associated with weakness of the body and one's will. What is not known is that there is nothing as bad to a blind person as misplaced sympathy. It would actually boost the man's esteem if the pastor acknowledged the rightfulness of the man's decision to stand and give his wife the seat.

For the same reason of misplaced sympathy, many a blind person is denied opportunities to participate in Church functions for fear that the Church would be straining him or her. Although many a blind person can stand at the door of the Church and give Church bulletins to incomers, this does not happen. We are left wondering whether it is misplaced sympathy or the thought that it would be a bad sight for the Church. Although many visually disabled people wash their own dishes at home, no blind woman may be allowed to help with the washing of dishes after a Church meal. This can also be attributed to misplaced sympathy.

The only ironical position many blind Church-goers seem to be readily accorded is singing or playing an instrument. This is done more often because of the mystery associated with it in the minds of many Ministers. Perhaps they quip silently, 'Oooh, so he or she can sing?' A common one in such instances is, "If he or she can do it without sight, what about you?"

Very few blind Ministers have been given a chance to practice shepherding even when they are qualified for it. A friend sadly lamented to me how he had been quietly kicked out of a parish because it was thought he could not carry out his pastoral duties the way his sighted counterparts did. He was kicked out on the pretext that they were being sympathetic to his condition and plight. Not a very good sight.

Mobility

Not only are several Church buildings inaccessible due to location, the architectural designs often do not take the needs of the visually handicapped into consideration. Consider a sanctuary that has several uneven stair arrangements, often with nothing to warn a blind man that he or she is coming near a step. Consider the high platforms without guard-rails. There are many offices without Braille labels on them. Besides, many Churches in the urban centres do not have stop signs or Zebra Crossings to allow easy access. What is more, many motorists even Christians do not slow down at Zebra Crossings. The society has acculturated Christians to behave like their secular counterparts.

In short, the Church is more eager to exorcise the “spirits of blindness” from visually disabled persons than to readily incorporate them in Church life and show them the love of Jesus. Such persons end up being more of a liability than an asset to the Body of Christ. It would be more Christ-like to reach out and show love than to use PWDs as possible displays of signs and wonders!

Barriers Affecting Persons with Speech Disability

Reference to persons with speech disability includes those who cannot speak with their mouths at all, and those who have speech deficiencies, e.g. those who stammer, slow speakers and those who have dyslexia. In instances related to speech, two common barriers are to be found in church: impatience and denial of opportunities. We shall examine these two factors in detail.

Impatience

A story is told of a man who had a room-mate who had a stammer. Let us call him Simon and his friend with a stammer, Peter. Simon and Peter lived on the fifteenth floor of a storey building that had no lift. So, to get to their room, they had to climb 225 stairs. One day, while working together at their workshop downstairs, they both realised that they had forgotten a crucial tool at their apartment.

“Quick! Quick!” The Simon told his housemate Peter, who had a stammer, “Come let us rush to get it!”

About climbing 20 stairs, Peter began to tell Simon something. “Stop wasting time, you lazy fellow! Hurry and let’s get this thing quickly!” Simon rebuked Peter.

Then Peter kept trying to speak, but Simon was adamantly rude: “Shut up! Let’s hurry!”

When they got to the door, panting for breath, Simon shouted at Peter, his house-mate with a stammer, “Open quickly, we must get this job done.”

“You have prevented me right from down there from asking you if you carried your keys because I left mine behind in our hurry!” Peter stammered through this revelation.

This scenario is repeated daily in the Church. Right from the Church leadership to the members, the speech impaired are hardly given a chance to fully express themselves. They hardly share testimonies or air their point of view at Bible study fellowships. Many a Church member is eager to make their point heard. However, they are not keen to hear those of the speech-impaired. What would Jesus do?

Denial of Opportunities

Many people with speech impairments can perform many types of tasks. They can make excellent builders, instrumentalists, cleaners and cooks among other trades. It is quite obvious that what they lack is the ability to express themselves in speech. However, they are denied opportunities to serve in these capacities because members think that their performance would be affected by speech. Hardly is a person with speech impairment given a leadership role or allowed to teach, or serve on a Church board.

Yet, did not God use Moses, a person with a stammer, to lead Israel out of Egypt? God dismissed Moses’ excuses of wanting to be left out of leadership due to a speech deficiency. Has the modern Church learned the lesson? This is what we read: “Moses said to the Lord, “O Lord, I have never been eloquent, neither in the past

nor since you have spoken to your servant. I am slow of speech and tongue.” The Lord said to him, “Who gave man his mouth? Who makes him deaf or mute? Who gives him sight or makes him blind? Is it not I, the Lord?” (Ex 4:10-11)

Concluding Remarks

It is obvious that, the Church, as part of the larger society harbours many obstructive attitudes, beliefs and practices towards PWDs. This contrary position continues to impede several unhealthy barriers to the inclusion of persons living with disability into her faith life. Although we have discussed four main groups, each with specific (albeit related) circumstances, every person living with disability is affected regularly by at least one or a combination several of the barriers to inclusion in Church life. These include the following:

1. Illiteracy makes it difficult for PWDs to read the Bible or any other Church material.
2. Poor communication which is manifested differently in people with different handicaps.
3. Stigmatisation which always locks people with disability out of mainstream Church activities.
4. Poverty which is often imposed by the society, and without doubt the Church.
5. Isolation which is often used as a means of hiding PWDs because they are perceived as disgraceful in the family.
6. Disease which is not attended to with the commitment given to people living without disability; many are left to die as a means of getting rid of the handicap in the family.
7. Religious beliefs and practices which often are camouflaged as theological positions, revelations from God or mileage for “healing ministries.”

The Church needs to consider a few possibilities that can urgently remove these barriers. First, there is a definite lack of knowledge about what the Scriptures teach on disability. Besides, emerging

information about the lives lived by persons with disability tends to shock many a Church Minister. Therefore, a proper, sound theological instruction is needed in order to specifically address this question from a biblical perspective. It is particularly this need that makes this Writers' Workshop (from which this book has emerged) something of an urgent necessity.

Second, there is a definite cry for Church ministers to be educated on the reality neglecting ministering to PWDs. Most PWDs are ignorant of key issues in this area. This does not need long periods of study. Seminars organised to create awareness for pastors and other Church leaders in this area would be sufficient.

Third, Christians living with disability should be given a chance to assist the Church in removing the barriers discussed in this Chapter. This can be done through overt ministry opportunities accorded them by the Church and by example.

Fourth, it is time for the Church to include in her annual budgets expenditure on programmes and supportive equipment that would promote the inclusion of people living with disability in regular Church life.

Lastly, the clergy should lead in the Christ-like example of spending time with and including the disabled persons in their day-to-day life. They should invite them to their own homes, spend quality time with them and get acquainted. Most importantly, such persons need to be regularly included in Church services, fellowships and activities as a means of integration so as to remove obvious barriers like isolation and stereotyping.

Disability, Society, and Theology

CHAPTER TEN

Education, Employment, and Health: A Disability Perspective

Anjeline Okola

While people in the rich world are talking about Independent Living and improved services, in Africa we are talking about survival. (By Joshua Malinga – a leading disability activist from Zimbabwe and a past Chair of Disabled Peoples International (DPI).)

Introduction

Education, employment and health are the core indicators of development. To determine the Human Development Index (HDI) of a country, the United Nations Development Programme (UNDP) uses data from education, employment and health collected at the national level. Therefore, literacy levels, rate of unemployment and life expectancy are key in composing the HDI.

In most countries in Africa, provision of basic health services, water, sanitation, roads, bridges, education and security are the responsibility of the state. Where there are limited resources, the state may not avail all these services to all citizenry. In such cases, the most affected are marginalised groups and persons with disabilities (PWDs) because they are disadvantaged. They cannot provide for their families because of their economic situation.

There is a close relationship between poverty and disability. Incidences of disability among the poor are caused by malnutrition – mothers are weakened by frequent childbirth, inadequate immunisation programmes and accidents in overcrowded homes. These factors somehow contribute to disability.

From a different perspective, disability creates and exacerbates poverty by increasing isolation and economic strain, not just for the individual but for the family. Hence, there is no doubt that in poor countries, PWDs are amongst the poorest. Poverty leads to lack of education, employment or access to health services thus making PWDs more vulnerable.

This Chapter discusses disability concerns in education, employment and health. It also looks at possible ways in which the government, disabled peoples' organisations (DPOs), churches and the general society can contribute towards inclusion of PWDs in these three areas.

Education

According to Byrne (1987), the primary aim of all educational effort should be to help boys and girls attain the highest degree of individual achievement of their potential. However, evidence suggests that achievement of personal goals depends largely on an individual's ability and available facilities, help notwithstanding.

Brian Dutton¹ once said: "Education brings PWDs in close contact with society and if you share a desk with a child with a disability in school, it's a lasting experience." For children with disabilities, access to quality education and thereafter to employment has long-term social and economic impacts.

The development of the entire society is at stake when children with disabilities are excluded from primary education. Therefore, their access to education should not be solely a personal and family issue. Social exclusion is a key dimension of poverty.

¹Brian Dutton is the director general of Leonard Cheshire Disability.

Although equality of opportunity in education has long been espoused, the reality has been rather different. According to the latest UNICEF (2007) statistics, 90% of children with disabilities receive no formal education. Even if the school is physically accessible, many children with disabilities remain excluded. This is especially common in rural areas in Africa. Two factors contribute to this state of affairs: first, some parents fear that their disabled children will not cope. Second, others do not think that it is worthwhile to invest in children with disabilities.

According to a research done by Verma (1998), children who do get education often receive inferior treatment. As a consequence, they have low expectations of themselves and from others and do not get the support they need in order to equally participate in society. Children with disabilities often have fewer demands placed on them and therefore may learn less than non-disabled siblings even in an informal setting.

Right from the start, they are excluded from many of the day-to-day interactions that are taken for granted. Access to education should not be seen only as a question of overcoming cultural barriers. There is a long held perception that it is actually “the key to liberation” (Bryne, 1987). As Verma (1998) found out in her study, it is widely regarded as the key to freedom from financial hardship, poverty, and boredom. Educational attainment can largely determine the type of occupation, level of pay and other life attractive qualities.

Oliver (1985) points out that the existence of segregated education for children with disabilities is part of the repressive state apparatus. It does not foster the development of societies as it removes the child from ordinary schools due to their impairment and therefore encourages exclusion. According to UNESCO, inclusive education starts from the belief that the right to education is a basic human right and the foundation of a just society. Therefore, inclusive education is a further modification of integration to make services more accommodative of learners with disabilities, rather than learners with disabilities being modified (Macha, 2008). The old view of integration suggests that children who are different have

to be accepted and tolerated. After all, the different have come to accept and tolerate their differences so why shouldn't everyone else? In order to be effective, inclusive education requires investment in building a barrier-free environment (Miles, 1999). Inclusion is therefore a basic requirement for tackling poverty (Heumann, 2005). This involves appropriate teacher training, curriculum development and provision of the necessary support for children with disabilities.

Inclusion of children with disabilities in mainstream education is a human rights issue. It is particularly important for effecting a positive change in broader societal attitudes towards eradication of disabling barriers. Families and communities must be supported to recognise a child with disability's value and human dignity from birth. Without this, the child will face an uphill battle characterised by discrimination that could prevent opportunities of early childhood education and school enrolment. Inclusion is a prerequisite to equality for all (Bayliss, 2005). However, Miles (1999) has argued that teacher-attitudes, physical accessibility of schools, transport and access to orthopaedic material and equipment are issues that also need to be addressed.

Special attention needs to be given to inclusion of children with profound and multiple learning difficulties in education programmes. Community based strategies should be promoted to keep children in local schools, to avoid long-term institutionalisation. Educational policies should ensure that children attend local schools and that financial arrangements are put in place to pay fees. This has been captured by the "UNESCO EFA Flagship: The Right to Education for Persons with Disabilities: Towards Inclusion" as discussed below.

The UNESCO EFA Flagship

The "UNESCO EFA Flagship: The Right to Education for Persons with Disabilities: Towards Inclusion" is one of the most recent main activities in inclusive education. Introduced by UNESCO, this Flagship was formed by an alliance of diverse organisations. These include global disability organisations, international development agencies,

intergovernmental agencies, and experts in the fields of special and inclusive education from developed and developing nations. The key purpose of the Flagship is to act as a catalyst in ensuring that the right to education for PWDs is realised. It also aims at ensuring that the goals of the Dakar Framework are achieved.

As Kristensen (2004) observes, education for learners with special needs has experienced massive changes during the last decade in some countries including major shifts in attitude and awareness. For example, the act of hiding children with disabilities is no longer common. Many parents now understand the need to educate these children. These changes not only benefit and enrich the lives of children with disabilities, but also enhance the learning experiences of all children.

EFA refers to access to the basic learning needs of all children in society. It includes tapping individual talent and potential, and developing learners' personalities, so that they can improve their lives and transform their societies. Miles (2007) in his research found out that the vast majority of basic learners in Africa do not go past primary school. From a policy perspective, there is a relationship between one's early (basic) education and his or her contribution to society. Therefore, provision of education including life skills is important for one to contribute creatively and productively at both family, community and society levels.

Using EFA guidelines, stakeholders in education can identify gaps in national education policies and strategies and take steps to ensure that every child has access to quality education. This will ensure that the educational school system accommodates the special needs of PWDs.

An essential component of national planning is to show how pedagogical processes can be made 'learner friendly' for all. Then, optimum learning can take place for everyone regardless of their ability/disability. This will guarantee that PWDs will successfully complete their basic education.

However there is still much work to be done to ensure that such plans truly take into account the needs of all, especially PWDs.

One of the determining factors is the type and extent of disability. To attain this goal, three factors are important in general education settings: first, tolerance of PWDs who have special needs. Second, the teachers should be given sufficient training, and third, the learning environment should be equipped with the necessary tools. These include physical aids, teaching and communication materials, and where possible availing extra personnel and teaching assistance as the situation may demand.

Some governments have resisted *Inclusion* as a system of education to accommodate children with disabilities. To overcome such barriers, this struggle has to be broadened beyond the narrow realm of merely education. When agitating for change, the relationship between education and the economy must be clearly demonstrated. For too long, PWDs have been left out of the workforce due to lack of necessary skills. To this extent, the demands of the labour market and education have been major impediments to the progress of PWDs as discussed below.

Employment

Article 23 of the Universal declaration of Human Rights states that:

Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.²

Alan (1997) advances several reasons why engaging in paid work is considered important. First, paid work is the only accepted means of earning a living, unless one has private means of income. Second, it is mostly through work that we make contact with the outside world and obtain a sense of belonging. Consequently, paid employment has become so important that Stone (1984) correctly observes that society is divided into those who can work and those

²The Universal Declaration of Human Rights, Article 23.
<http://www.un.org/en/documents/udhr/>

who cannot. Indeed Finkelstein (1980) argues that the disability category was created as a consequence of exclusion of PWDs from the labour market during industrialisation. He further observes rightly that a job represents the opportunity for PWDs to prove to others and to themselves that they are as good as anyone else.

Employment opportunities for PWDs in developing countries are often almost non-existent. Consequently, many PWDs have to beg for a living whereas, in actual fact, employment is the only way out of lifelong exclusion.

Causes of Unemployment

Most children with disabilities are secluded from society during childhood. Therefore, as they grow up, their non-disabled peers may not be aware of their existence, let alone their value and rights as equal citizens.

Alan (1997) rightly states that PWDs seem to have restricted employment opportunities. The main causes, he reiterates are discrimination and lack of education, experience and confidence. According to Murray (2008) other barriers include stigma, prejudice, low expectations and inaccessible education, transport and workplaces.

Remedy

It is important to raise awareness amongst employers about disability issues and that there are benefits in having PWDs as employees. These benefits according to Murray (2008) include commitment, reliability, the possibility of government incentives and improved public image.

Various Disability Acts in most countries call for enforced by law of employment quota systems for PWDs. However, it has been observed that employers tend to view enforced employment as fulfilling a duty. This can increase the marginalisation of PWDs. Governments should therefore offer incentives, rather than penalties, to encourage employers to hire PWDs. Employing PWDs should

be seen as a business decision rather than an act of charity (Knowles, 2005).

Coleridge (2005) advances a rather practical argument that, the terms 'jobs' and 'employment' may not be useful concepts. Many PWDs live in the rural areas and depend on the informal economy such as near-subsistence agriculture. Only a few PWDs live in urban areas where relevant skills are essential for employment. Therefore, employers' views need to be widened to include the idea of 'competencies' when recruiting. This is a more useful approach because it includes knowledge, skills and attitudes (Coleridge, 2005), which even PWDs have.

A human rights perspective on these issues does not mean that PWDs should have a right to a job. On the contrary, it means that PWDs should have an equal chance of employment like everyone else. This means equipping PWDs with relevant skills and values so that they can compete fairly with others in the labour market. It also means ensuring that the market operates in such a way that it does not discriminate against them.

An example of this human rights perspective is what is being advocated for by ILO's employment creation scheme for PWDs. This scheme encourages acquisition of vocational and business management skills and proposes supporting business start up.

Among the policies ILO proposes are:

- Governments to build vocational rehabilitation and training institutes where PWDs can be trained to make and sell finished products to the general public. This can lead to self sufficiency.
- Supported employment in which PWDs are employed for job coaches to work together with them. This is effective for those with cognitive and psychological disabilities.
- Wage subsidies whereby the government pays all or some of the wages of PWDs. These can lower barriers to private sector hiring and also provide job experience.

- Accommodation subsidies by the state to make the workplaces accessible can be effective in beginning to change social attitudes.
- Disability management programmes aimed at people who become disabled at work.

Sustainable Microfinance

Access to microfinance facilities is essential for PWDs because it can enable them to be self-employed. Coleridge (2005) observes that the following factors need to be considered to make the programmes more beneficial to PWDs:

Knowledge Gap

The knowledge gap between PWDs and microfinance institutions must be addressed. Although micro-credit is a popular and powerful development tool, PWDs are not its benefits as well as disadvantages. Mersland (2005) argues that the limited spread of micro-credit to PWDs who are entrepreneurs is caused by the “knowledge gap” between them and microfinance institutions. Therefore, they should be well informed about micro-credit to avoid debt problems.

Concerning demand, advocates of micro-credit for PWDs seem to have a knowledge deficit regarding some important aspects of micro-credit. Similarly, suppliers of credit like microfinance institutions seem to lack information on disability issues.

Ethical Approaches

Microfinance institutions must take an ethical and informed approach in promoting micro-credit to PWDs. In offering loans, they must professionally assess and evaluate an individual’s capital resource base, competency and context. They can then determine without bias whether or not micro-credit the person should get credit.

A common approach is to promote special loan products designed for entrepreneurs with disabilities. They usually subsidise interest rates for entrepreneurs with disabilities and have special

credit components promoted by DPOs. This presupposes that the main reason why entrepreneurs with disabilities fail to borrow is due to inappropriate loan products. On the contrary, low access to microfinance among entrepreneurs with disabilities is not caused primarily by inappropriate products. The underlying problem is adverse selection where microfinance institutions are unable to assess the resources of disabled clients. Microfinance institutions need to assess the entire resource base of clients to minimise adverse selection. An entrepreneur requires physical capital, human capital and organisational capital resources.

Evidence-Based Approaches

In issuing out loans to PWDs, the decisions made by microfinance institutions need to be based on research. They should go out of their way to determine the demand for micro-credit by PWDs. The results of the research should be used to develop a categorisation of demand. This can be used in turn to provide guidelines for assessing suitability for micro-credit.

Too little knowledge makes it hard to reveal the real human capital (competencies) of disabled entrepreneurs. Research shows that the impact of micro-credit is greater for clients starting with more financial, physical and social resources. It therefore follows that the impact is less for clients starting with a very limited resource base. The circumstances are even worse for clients with limited resources as it might even aggravate the situation.

PWDs represent an enormous market for microfinance institutions. As observed however, micro-credit is only a powerful poverty alleviation tool if applied to persons with the necessary resource base to make effective use of loans.

Inclusion of PWDs – microfinance institutions should take the lead in appropriately supporting PWDs to be self-sufficient. As clients, this will give them an equal opportunity with non-disabled persons to compete fairly in business.

Healthcare

According to World Health Organisation (WHO), health is the complete state of physical, mental and social well-being – not merely the absence of disease or infirmity. All PWDs have the same needs for basic health services as everyone else. However, most of PWDs around the world lack access to appropriate medical care and rehabilitation services. This is especially the case for those living in low- and middle-income countries (WHO, 2007). Lack of social services further creates a barrier to full inclusion and participation in all aspects of life (Hesperian, 2007). As a consequence, PWDs experience greater challenges in attaining and maintaining maximum independence and health.

The Convention on the Rights of PWDs requires countries to ensure that PWDs are provided with appropriate health services. These include general healthcare, habilitation, rehabilitation services and non-discrimination in the provision of healthcare (Articles 25 and 26). The Hesperian Foundation (2007) argues that towards the attainment of this convention, governments should actively support implementation of the UN Convention in these areas. WHO suggests that in order to improve medical care and rehabilitation services, Governments should:

- Develop normative tools, including guidelines and a global plan of action, to strengthen medical care and rehabilitation services.
- Support hospitals to integrate medical care and rehabilitation services into overall primary healthcare.
- Support the development of Community Based Rehabilitation Programs (CBR).
- Facilitate the strengthening of specialised rehabilitation centres and their links with CBR.
- Promote strategies to ensure that PWDs are knowledgeable about their own health conditions, and that professionals support and protect the rights and dignity of PWDs.

A major breakthrough in health was witnessed during the Fifty-eighth World Health Assembly in 2007 which adopted a resolution aimed at improving the daily lives of PWDs. It called on WHO and its Member States to work towards ensuring equal opportunities and promoting the rights and dignity of PWDs, especially those who are poor. Countries were requested to strengthen national policies and programmes on disability, including CBR services. WHO in turn was requested to support these efforts, and to collect more reliable data on all relevant aspects of disability, including the cost-effectiveness of interventions.

Specifically, the resolution called upon countries to:

- Promote early intervention and identification of disability, especially in children.
- Support the integration of CBR services into the health system.
- Facilitate development and access to appropriate assistive devices like wheel chairs, hearing aids, orthoses and prostheses. These would help to ensure the inclusion and participation of PWDs in their societies.
- Strengthen collaborative work on disability across the United Nations system and with Member States, academia, private sector and Non-Governmental Organisations (NGOs), including DPOs.

The Hesperian Foundation (2007) singles out habilitation and rehabilitation as the key issues that enable PWDs to be integrated into the society. These are the processes intended to enable PWDs to reach and maintain optimal physical, sensory, intellectual, psychological and/or social function.

Rehabilitation encompasses a wide range of activities including rehabilitative medical care, physical, psychological, speech, and occupational therapy and support services. Habilitation on the other side refers to the process of enabling PWDs to develop skills and

participate fully in the community. It is usually an ongoing process which enhances the quality of life of PWDs and empowers them towards self-determination. Nonetheless, Morris (1996) insists that PWDs should have access to both general medical care and appropriate habilitation and rehabilitation services.

Community-Based Rehabilitation

CBR focuses on enhancing the quality of life for PWDs and their families, meeting basic needs and ensuring inclusion and participation. CBR is a multi-sectoral approach which was developed in the 1980s, to give PWDs access to rehabilitation in their own communities using predominantly local resources. A 2004 joint ILO, UNESCO and WHO paper repositioned CBR as a strategy for rehabilitation, equalisation of opportunity, poverty reduction and social inclusion of PWDs.

Looking at the current concern on health, the goals of CBR should be to ensure the benefits of the Convention on Rights of PWDs reach the majority by:

- Supporting PWDs to maximise their physical and mental abilities, to access regular services and opportunities, and to become active contributors to the community and society at large.
- Activating communities to promote and protect the human rights of PWDs for example by removing barriers to participation.
- Facilitating capacity building, empowerment and community mobilisation of PWDs and their families.

CBR has been implemented in more than 90 countries through the combined efforts of PWDs, their families, communities, relevant government departments and NGOs working in disability and development. Involvement and participation of PWDs and their families is at the heart of CBR.

Assistive Devices/Technologies

Assistive devices and technologies increase mobility, hearing, vision and communication capacities. These include wheelchairs, prostheses, mobility aids, hearing aids, visual aids, and specialised computer software and hardware. With the aid of these technologies, PWDs are able to enhance their abilities and live with a degree of independence and participate in their society life.

In many low-income and middle-income countries, only 5%-15% of people who require assistive devices and technologies have access to them. Production is low and often of limited quality. There is a scarcity of personnel trained to manage the provision of such devices and technologies, especially at provincial and district levels. In many settings where access might be possible, costs are prohibitive.

The Convention on the Rights of PWDs (Articles, 20 and 26), the World Health Assembly resolution WHA58.23 and the United Nations Standard Rules on the Equalisation of Opportunities for PWDs all highlight the importance of assistive devices. Countries are requested to promote access to assistive devices and technologies at an affordable cost. In addition, they should facilitate training for PWDs and professionals and staff working in habilitation and rehabilitation services.

Some of the obstacles faced include physically inaccessible health centres particularly in rural areas where one has to walk a long distance. Also, some health workers may discriminate against PWDs. Women with disabilities frequently complain of doctors denying them access to reproductive health services. They are denied safe motherhood and child survival; family planning; management of STIs and HIV and AIDS; promotion of adolescent health; management of infertility; gender issues and reproductive rights.

Of major concern to PWDs is the fact that information on healthcare is often not provided in accessible formats. Therefore, health education programmes do not adequately target PWDs. Some PWDs have specific medical needs associated with their impairments. Some may require access to psychological expertise. Meeting such

needs is a prerequisite for achieving full participation of PWDs in society.

Way Forward

We need to borrow heavily from the Principles for European Union Delegations (EU 2006) and Services on how to proceed in the area of disability and development. This is because it gives a broad idea on what governments, NGOs and other civil actors should be doing which is:

Pursue a Twin-Track Approach – there is a need to both mainstream disability issues across all relevant programmes and projects and to have specific projects for PWDs. Disability concerns such as transport and infrastructure should be recognised by international development partners. They should also be addressed through specific disability projects (including capacity building) for PWDs.

Ensure the Inclusion of PWDs – the rallying call is ‘*Nothing about us without us.*’ Stakeholders should ensure that PWDs participate in the development of any programme designed to benefit them. A starting point for ensuring that PWDs are fully included is to ask them what their needs are. Nobody knows as much about disability and the processes of exclusion as PWDs themselves. It is essential to consult regularly with representatives of DPOs.

Include PWDs in the Workforce – an inclusive organisation working on poverty issues should employ a reasonable proportion of PWDs among their staff. However, working with specific quotas has a mixed record and does not necessarily improve the overall situation.

Facilitate and Support Capacity Building of Representative DPOs – there should be deliberate efforts to facilitate the process of establishing or strengthening DPOs. This could be supported

through funding of capacity building for organisations of PWDs and their families to empower them and thereby increase their influence in decision-making. It is also important to support organisations responding to the needs of PWDs. These include parents' organisations, professional organisations for social workers or special teachers and wider organisations that include PWDs such as women's or youth organisations.

Conclusion

Governments rarely consider the needs of PWDs when formulating their development agenda. In most cases, they do not make sufficient effort to consult PWDs or their representatives. Many donors, aid agencies and mainstream development cooperation including NGOs do not consider the particular needs of PWDs in their programmes or projects. Many do not have or practise policies of disability equality and thus exclude PWDs from their activities. As a result, development cooperation largely excludes PWDs.

However, the social and human rights approach to disability is being adopted gradually by Governments and international institutions. It has taken the mode expressed in the World Action Programme (1982), the UN Standard Rules (1993), the International Classification of Functioning, Disability and Health (ICF, 2001) and the International Convention on the Rights of PWDs.

CHAPTER ELEVEN

Society and Leadership: Challenges and Opportunities for People with Disabilities

Esther Mombo

“But Moses said to the Lord, ‘O my Lord, I have never been eloquent, neither in the past nor even now that you have spoken to your servant; but I am slow of speech and slow of tongue.’”
(Exodus 4:10)

“Leadership can be defined as the will to control events, the understanding to chart a course and the power to get a job done cooperatively using skills and abilities of other people. Its power is grounded in mutual consent, expectations and commitment”

Donald G. Krause, *The way of the Leader*.

Leadership in Africa has many faces. Most have been shaped by unique socio-economic constraints and religious factors. But in general, Africa suffers from poor leadership in all spheres of life—political, social, economic and religious. Leaders raise the people’s expectations in equal measure, only to disappoint and negate them. Indeed, it is very difficult to find model leaders in contemporary Africa. Worse still is the suffering which unscrupulous leaders cause and hide behind their ethnic communities and stir ethnic hatred.

The failure of leadership on the continent has led to the recent interest in leadership and leadership studies. Many books and training

manuals have been written and numerous courses, seminars, and conferences on leadership held to identify, promote resources and monitor leadership development. Many leadership experts (for example, Stephen Covey) visit various countries to inspire men and women on true leadership.

The prospect of people with disabilities taking up leadership positions in the church and church related remains remote. The reason is, while the society outside the church is changing fast and now accommodates different people in leadership positions, the church still lags behind.

Other groups excluded from leadership positions are women and the youth. While many women have been accepted and are now leaders in church, there has been little focus on the youth and people with disabilities.

This chapter outlines some of the factors that hinder people with disability from realising leadership positions. The chapter also analyses the reasons why it is necessary to address these challenges. It also looks at how opportunities in theological education could pave the way for leadership for people with disability who study in such institutions.

The Bible and Leadership for People with Disability

The Old Testament

The Old Testament is the story of the Jewish people who were led by priests, prophets and kings. Priests were very important because they served as intermediaries between God and the people. In those days, priesthood was hereditary. So, the cultural settings and the scripture influenced the way these priests were chosen.

The Bible says a lot about issues of disability and leadership in general. The priests, kings and even prophets of Israel all appear to have had no disability. However, among the men called to lead God's people from bondage to freedom was Moses. Moses had a stammer, meaning he could only speak with difficulty, hesitating and repeating words. And yet proved to be God's mighty spokesman.

In spite of his disability, God chose him to lead His people. He gave him Aaron, as a helper (Exodus 4:10). Apart from Moses, we are not told whether any other public leaders had any disability. The reason may be that, the regulations for priests clearly stated that no one with a disability should be appointed as a leader. It is written the book of Leviticus as follows:

The LORD said to Moses, “Say to Aaron: ‘For the generations to come none of your descendents who has a defect may come near to offer the food of his God. No man who has any defect may come near: no man who is blind or lame, disfigured or deformed; no man with a crippled foot or hand, or who is hunchbacked or dwarfed, or who has any eye defect, or who has festering or running sores or damaged testicles. No descendant of Aaron the priest who has any defect is to come near to make offerings made to the LORD by fire. He has a defect: he must not come near to offer the food to his God. He may eat the most holy food of his God, as well as the holy food; yet because of his defect, he must not go near the curtain or approach the altar, and so desecrate my sanctuary. I am the LORD, who makes them holy (Leviticus 21: 16-21).

This means a priest as a leader had to be a male person with no physical disability. An overview of the Old Testament shows that there was no room for people with disability to become leaders. It is also clearly indicated in the books of Exodus, Leviticus and Numbers that only the sons of Aaron and the descendants of Levi were to be made priests. Deuteronomy notes that the descendants of Zadok could also become priests. It is painful to realize that even though leadership was hereditary, still the disabled heir-apparent was discriminated against.

The New Testament

The New Testament is a collection of 27 books, written by different authors over a period of about 50-120 years. There are four gospels which reflect the earthly life of Jesus Christ. They document His teachings and activities. The apostles also document the activities

of the early church shortly after the resurrection of Jesus (Acts 1:4-9) up to the death of Paul.

The epistles were written by different authors and addressed to different churches and individuals. They were to be used as teaching tools by new converts and church congregations that professed faith in Jesus Christ.

The earliest epistle of Paul (to Galatians) was written around 50-55 AD. The last letters were most probably the Pastoral Epistles (I and II Timothy and Titus), written in the second century (90-120 AD).

The book of Revelations or the apocalypse is a family of literature that uses visions, symbols and metaphors to communicate its message. This is primarily because it is resistance literature that arises from political oppression and persecution.

As far as issues of disability and leadership are concerned, we see differing views in the Bible because of the context of the time. Jesus appointed twelve men known as disciples. They have been described as ordinary men whom God used in an extraordinary manner. Among the twelve: four were fishermen, one a tax collector, and another, a revolutionary. The fact that they were all men has remained an issue for women's leadership in the church throughout the ages. Also, we are not told whether any one of them had a disability. This can be associated with how people with disabilities were treated in society – outcasts – especially as far as leadership was concerned.

Jesus understood his context, and when he began his ministry; His manifesto included healing of the sick, bringing sight to the blind and treating other illnesses (Luke 4:18-19). He understood the fate of those who had different disabilities. When a person with disability was brought to him, he healed them both spiritually and physically. Even as Jesus healed those who had various physical disabilities, in His teaching, He implied that people with disabilities had a place in the Kingdom of God (Luke 14:15-24). The inclusion of people with disability in the parables is an indication that Jesus knew that they would always be around and should be included in the life of any

society. He was also aware that the attitude of society towards people with disability would not change just by the miracles he performed.

Some scholars (like Nancy Eiseland) have noted that Jesus was a 'disabled God'. This, they point out is true because of His incarnation, death and resurrection. When he rose again from the dead, His body had marks of disability. This is an indication that using His life and ministry as an example, society should not discriminate against people with disability.

Early Church and People with Disability

The early church was inaugurated as an institution that defied all social barriers of the time such as gender, race, ethnicity and class (Acts 1 and 2). The disciples of Jesus continued his healing ministry. Healing is among the first miracles after Jesus' 'death' that Peter and John performed at the gate of the temple (Acts 3:1-10).

The leaders were chosen based on the needs and social context. For example, the seven deacons were chosen to serve the needs of the widows of another ethnic community (the Greeks) (Acts 6:3ff). Throughout the book of Acts, people with different forms of disability are healed.

The Apostle Paul was converted in the early church and called to be a missionary. He had a disability which he described as 'a thorn in the flesh' that persisted in spite of his prayers and mystical experience (2 Corinthians 12: 1-10). Paul was forced to live with his disability and bear criticism that his disability was as a result of his own sinfulness, or a combination of other woes. Physically, Paul was never healed but God gave him sufficient grace to cope with the condition and the stigma that went with it.¹ On leadership principles, Paul was influenced by the context rather than his own disability. He argued on the basis of gender as indicated in his pastoral

¹Bruce G Epperly *Healing and Hospitality in Jesus Ministry Graduate Theological Education and the Human Experience of Disability*. Birmingham: Harworth Pastoral. 93

epistles of Timothy and Titus. He elucidates the person and office of a leader. The leader of the church had to be a man married once (1 Timothy 2: 11-12 and 1 Corinthians 14:34-35). The place of people with disabilities appears not to have influenced the choice of leaders in the early church.

Church Fathers and People with Disability

The Church Fathers did much to influence the institution of the church in its theology and structures. On leadership, the church fathers were impacted by their context and the interpretation of scriptures both in the Old and the New Testaments. It appears that the Levitical code and the ministry of Jesus and that of Paul guided thinking of the Church fathers on leadership. Therefore women and people with disability seem not to have been included in the church hierarchy. The development of the Church offices excluded women and some men so that with a three fold ministry of the church we had a Bishop, priest and deacon.

It is not clear how many of the church fathers had disabilities. We know of Origen who was disabled in one part of his body and remained serving in ministry. In both the Roman Catholic and the protestant church traditions, men with disabilities have been excluded from official church leadership

Mission Christianity and People with Disability

The forms, nature and attitude to people of disability in regard to leadership positions emanates from the way the Christian faith was founded. Christianity was established in this continent by various mission agencies from the North. The first converts to Christianity were largely gentiles, social outcasts and people with disability. The church became a refuge for them and a space for upward social mobility.

Prof. Zablon Nthamburi notes that after the Methodist Mission Society preached at the coastal region of Kenya for some time, the

first convert was a cripple.² At each mission station, there was a centre or school that catered for people with disability. While social outcasts rose to positions of leadership, people with disability received some form of education that paved the way for them to serve in the society at large.

In the initial years, the numbers were few because people with disability were hidden indoors. No family wanted the public to know that a child or adult with disability existed in the home.

Theological Education and People with Disability: Case Studies

Case Study 1

Samuel Kabue of Kenya has a visual impairment. When he wanted to join the ordained ministry he was denied a chance at college. Even his own local church who knew him well refused to support him. Even though he had the necessary academic qualifications, no one was ready to second him to train for the ministry.

He notes in his story that his local church could not recommend him. They refused to stand surety for him and support his eligibility or suitability to serve in the ministry. After completing his university education, he tried again to join the ministry. But, just like before his local church refused to endorse him.³ In the end, Kabue did not train for the ministry but joined an ecumenical organisation that has helped to raise issues of disability.

Case Study 2

Guku is a 25 year old Kenyan woman living with a physical disability. When she finished high school, she went to a private college to study a course that the family thought would help her. She had

²Zablon Nthamburi : *A History of the Methodist Church in Kenya*. Nairobi Uzima Press 1982.

³Arne Fritzson and Samuel Kabue *Interpreting Disability: A Church of all and for all*. Geneva: WCC 2004. 42-43.

difficulties doing the course because she had wanted to study theology. The route to studying for a theology course was through secondment from the church.

When she requested the church for secondment, they told her it was impossible. One day, Guku met with a church minister who mentioned St. Paul's University as a possible place to study theology. The minister took her to the college to find out what possibilities were available for someone like her.

Guku was given information about how to join the university and the academic qualifications required. She could either join through sponsorship by the church or as a self-sponsored student. The church had refused to sponsor her. So, she opted to join as a self-sponsored student. Upon submitting a formal application, she was granted admission.

It later happened that Guku never took up her place at the university. Neither did she inform the university about her reason. After a semester, the university decided to find out what happened to Guku. The university sought her out because there was a course on theology and disability issues to be offered that semester. Therefore, the university thought it would be a nice idea to have a person with a disability studying on the course.

She was later traced to her home. Apparently she was unable to take up her university place because of lack of finances. Although the family was financially stable, they had chosen not to sponsor her to do a theology degree. The university sought and was able to find a partial sponsorship for Guku. The university offered her a partial grant for one semester on condition that the family pays for her accommodation. When she was given this option she was excited but had to check with the family first. Later, she called the university to confirm that the family had agreed to pay for her accommodation. The university discussed the matter with the family and requested them to visit and see for themselves the type of accommodation that would be available for their daughter.

After some time, she joined the university. When she arrived to begin her studies, her father requested the university to pay for

Guku to do a business degree. The officials involved with the arrangement were shocked. Remember, the grant was specific and could not be changed. Guku confirmed that her choice and main interest was to study theology. Her father then acquiesced that Guku could study the course of her choice.

After joining the university, Guku faced several challenges. The main problem was access to facilities like the computer laboratory and the library. The university had to re-organise some of these facilities in order to accommodate her special needs. Also, her room specifications had to be modified. She also had to be put in a hostel closer to the lecture rooms. After these adjustments, Guku settled at the institution and has been accepted as part of the university community. Asked how she has integrated into the university setting Guku attributes it to the fact that the community is friendly. She however regrets that the community involves her in some activities only minimally.

Kabue and Guku's cases raise four issues which I would wish to highlight. First, people with disabilities feel called to serve God and the church, just like able bodied people. Second, the church seems to be reluctant to support people with disability for ministerial formation. Third, some families think negatively about theological studies. Therefore, the willingness to provide financial support is lacking and most students have to depend on grants. Fourth, are the colleges prepared to receive and train people with disability? That remains the challenge to many training institutions.

Anderson points out that because of an able-bodied centred worldview, people with disabilities are silently marginalised within theological education.

It is no wonder that it has taken institutions of theology a long time to make space for people with disability. Since the churches are responsible for financing ministerial formation, they are reluctant to support people with disabilities to studies for fear of what other churches may say. These fears emanate from the cultural context

of the reading and interpretation of the Bible on disability. In this regard Wilke (2003) has noted that:

the contemporary church harks back to Leviticus, thus the role of a priest is ‘a man for others,’ the ‘one for others.’ ‘this role before the congregation’ – in front of the congregation’ – up front – is very public in administering the sacraments, preaching the word, and being of service to other human beings within and without the congregation.’⁴

As well as the Bible, there is the social construction about people with disability within society. The view is that people with disability are not full human beings thus things are done for them and they cannot do much for others.

Economically, theological education is regarded as an investment by the churches. Therefore, the process of selection marginalises the disabled people even if they have a call for the ministry. For families, there is also a dilemma to pay for theological education especially if they are not sure of the job opportunities after studies. In order to accommodate people with disabilities, special funding is necessary in these initial stages.

The issues raised above account for the few people with disability in theological institutions. Few of them take up leadership within the church. It is easier to find people with disabilities in secular leadership than in the church.

Challenges of Leadership

Leadership has to do with power, and it is those with power who determine who should be included or excluded. Those with power determine the norms of inclusion and exclusion. First, people with disability are marginalised from the places where they should be

⁴Harold H. Wilke *Graduate Theological Education and the Human Experience* *Graduate Theological Education and the Human Experience of Disability*. Birmingham: Harworth Pastoral, 2003. ‘ 2003: 12).

prepared for leadership positions in the church and society. The process of selection is not friendly to people with disability.

Second, many training institutions are not prepared to take on people with disability. The unpreparedness is both in terms of the physical infrastructure, the curriculum and teachers.

I noted earlier that leadership is about power. An analysis of power is therefore necessary in order to reveal its operation in reconstruction and reform. In order to analyse it, we have to examine the policies and the processes in theological institutions.

As much as there are many challenges for leadership opportunities, there are also opportunities. St. Paul's University is a case in point. The university has been at the forefront of teaching theology and disability issues. The course includes theology, social, cultural economic and political themes.⁵ A sign language course is taught at both introductory and intermediate levels. Students who have taken the course are able to minister to people who are of hearing impairment. Together with the curriculum, St. Paul's has begun a process of admitting people with disability alongside other people. Through this process it is hoped that the church will allow people with disability into positions of leadership.

By admitting self-sponsored students especially those with disability the university is saying three things.

First, it is a confirmation that people with disability are called to serve in the Church just like the able-bodied people.

Second, the study of theology and disability can only be done well, with those that live with the disabilities.

Third, by taking the first step to admit and train PWDs, the institution can seize this opportunity to improve its physical facilities, the curriculum, and faculty to suit the needs of the disabled.

⁵ Appendix

Disability, Society, and Theology

CHAPTER TWELVE

Disability: Social Challenges and Family Responses

Joseph Shiriko

Introduction

Many scholars and practitioners have defined disability from various angles. For the purpose of this Chapter, to have a disability means having a permanent physical or mental impairment that limits part or complete use of your body. In most cases, the challenge a person with disability (PWDs) faces is not the disability itself but negative social attitude. This is mainly manifested in individual thinking and feeling which in turn influences behaviour towards PWDs.

In this Chapter, the terms *community* and *society* will be use interchangeably. A community is a group of people who live in a particular area, with common social attributes such as religion, race or occupation. The community has certain specific features. They often have similar culture, attitudes, as well as a sense of belonging. The smallest unit of the community is a family unit. Therefore, many family units make a community.

Helander (1995) defines a community as follows:

a community consists of people living together in some form of social organisation and cohesion. Its members share in varying degrees of political, economic, social, and cultural characteristics;

as well as interests and aspirations, including health. Communities vary widely in size and socio-economic profile ranging from clusters of isolated homesteads to more organised villages, towns and city districts.

People in the community differ in terms of age, sex, socio-economic backgrounds, religion, profession, languages spoken, rituals practiced and different food habits. Despite these varied backgrounds and practices, the community is united and every member has a sense of belonging.

The community shares many variables such as interests, conflicts, work, joy, festivals and even resources like land, water and shrines. The members help each other in times of need, hunger, drought, harvest and calamities. They know each other and live together in unity while accommodating each others' diversities.

Community is a big resource including spiritual, economic, moral, political, environment, psychological, physical, material and power structure. The community with its sense of unity and sense of belonging means that their member will be helped in a situation of a threat from an external source. Because of a community's unwritten norms, people behave in certain ways. For example, they support neighbours in difficulties, greet each other politely and live in peace with neighbours. In this way, harmony and cohesion is maintained.

Social Challenges

In most African communities, there is a strong belief that nothing just happens. Everything is caused by a variable – whether figurative, real or imagined. The belief in especially the forces of “our gods” and “unseen spirits” has remained particularly very strong. This belief system has been passed on from generation to generation and is firmly embedded in society. Therefore, disability is also viewed in this context.

Beliefs About Causes of Disability

Within all communities across the continent, people have varied myths and misconceptions about causes of disabilities. For example, children born with disabilities are thought to be a result of the following situations:

1. Children conceived out of wedlock
2. Incestuous relations
3. An expectant woman doing certain practices that are taboo. These include eating eggs, having sex outside marriage when pregnant or when breastfeeding and killing an animal like a cat.
4. Laughing at a PWD.
5. Failure to respect and appease ancestors thereby earning their wrath.
6. Being revisited by family members who passed on long time ago.

Perception of PWDs

In light of the above beliefs, PWDs are viewed as mere consumers and useless dependants. They are not seen as producers of goods and services. Society believes that they are undergoing a deserved punishment.

Others are viewed as put there by gods to be intercessors and mediators for those still alive in the spiritual realms and the ancestors. Therefore, they are feared, protected and not antagonised lest society invokes the wrath of these spirits. There are very many other views depending on the circumstances, situation or community in question.

Therefore, negative attitudes are caused by expectations, cultural inclinations, behaviour, circumstances, information gap, stereotypes, and traditional views.

Church Perception

In some religious circles, PWDs are viewed as having little faith. Therefore, they have earned what they deserve because of their sin. Otherwise, they would have been healed of their infirmities through prayer.

Because of fear that everybody associated with them is likely to suffer the same fate, the church shuns them. In addition, members of the congregation may not want to have anything to do with the family of a PWD. Thus both the PWD and family members are unlikely to be given any position of responsibility in church. Some may quip in private *Kama ni kiwete atashikaje Biblia? Atatoaje huduma?* (*How can a PWD hold the Bible? How will he or she serve?*)

The Marriage Institution

Weddings are a big event in any church. Marriage is ordained and perfected by God. Just like everyone else, it is also the ultimate aim of a PWD. The church is at the front in promoting marriage as a holy institution and preaching family values.

Discrimination, Stereotype and Stigma

The pinnacle of total and effective empowerment is to be able to register achievements in marriages. PWDs want to enter the marriage institution like everyone else. They need to be supported to attain this goal.

However, how many weddings are witnessed including and involving PWDs? Has the community or congregation witnessed a wedding function of PWDs? Has there been one with a PWD? Has there been one involving a member of a family of or with a PWD?

Does your community or congregation believe that PWDs can make families? Do visually impaired persons bring forth children with visual impairment? How about the hearing impaired?

Do women with disabilities bear children? Can men with disabilities sire children? Do we discuss the subject of sexuality with PWDs?

These kinds of questions could go on and on. Are they relevant? Do we have people asking these questions? Is there someone to provide correct answers? Are there live examples to be seen in the community or congregation? Can we seize such opportunities to dispel such myths? Can this be another entry point for stigma reduction and attitude change?

In most of our communities, enquiries are made about various families when marriage proposals are made. Woe unto that family that has a PWD! This would be a reason, "... just impediment why these people should not be joined together in holy matrimony." And the church would agree with this! Is this not a good opportunity for the church worker to intervene and touch more lives?

Effects of Such Perceptions

What then follows is serious loss of identity and self esteem. Derogative names like *mulema*, *katyamba*, *musilu*, *kiguru* and *ojok* are used to describe PWDs, not their *regular* names. For example, if John has visual impairment, it is easier for society to identify him with his disability than his real name. Similarly, the whole family in which they are found is thus labelled (*abalema*, *ababofu*, *abasilu*, *abatimbe balia*; *amakara*, *amatonde kalia* [Those lame, blind, deaf, cripples, albinos]).

Therefore, PWDs face challenges in attaining levels at which they can start to find some ground to operate. They have to work extra hard to hivel themselves from the low positions thrust upon them by the community. The energy expended in climbing the social ladder becomes part of the disabling, discriminating and stigmatising forces.

How to Change Perceptions

The church can change such perceptions if it uses positive supportive scriptures as written in the Bible. For example, "we are all fearfully

and wonderfully made in God's image..." (Psalm 139:14) We are all made of body, soul and spirit. "Fear only that which can destroy both the body and soul." (Matt 10:28)

Church workers must therefore reposition themselves and make a fresh start. They should be ready to walk the long winding journey. Disability should not be an impediment to marriage. They should use relevant scriptures to make the community/congregation change their attitudes and accept all marriage unions even those between PWDS. They should accord opportunities to PWDs and family members to enter holy matrimony based on the true Christian faith, founded on love.

Since PWDs will always be among us, negative attitudes compound the disabling conditions. Only positive advocacy mechanisms can bring about change for the better.

The church is well positioned to play a crucial role in bringing about this much desired change for the benefit of all. This it can do through creative strategies of ministering and pastoral care.

Benefits from Positive Change of Attitude

There are many benefits to be derived from a positive change of attitude. First, opportunities for self development for all in the congregation will abound. Second, PWDs and their family members will be able to take up some responsibilities in church's activities at all levels. Third, family members will most probably grow and develop in their Christian pursuits having found the much needed space to operate.

They will be freer to participate in discussions and contribute ideas not only towards bettering their lot but also supporting the wider church and community activities and initiatives. There will be clearly visible partnerships and cooperation between the church, PWDs as well as their families. In this way, stigma associated with disability is reduced considerably.

True Causes of Disability

The church and the community at large need to be reminded of incidences that can cause disabilities that they can identify with. Every year, people are disabled through accidents especially on the road. Also, the 1998 Nairobi US embassy bomb blast apart from fatal effects caused impairment in varying magnitude. It also affected pregnant women and their children.

The Family

A family is a group of people who are related to each other, especially parents and their children. There are several types of families: nuclear, extended or single parent families. Employed and resident quasi caregivers also form part of the extended family. Any family member with a disability makes society refer to that family as one with a PWD. Any community initiative that does not recognise the family as an institution and involve it appropriately risks failure.

Family Stability

The family needs to enjoy stability and unity at all times. It is from stable families that we derive stable congregations, communities and by extension, nations. When any social discomfort afflicts the family, its stability is shaken and destabilised. This becomes a very big threat to its cohesion. One such social discomfort is the presence of a PWD.

Parents' Reactions to Disability in the Family

Every family wishes to see its identity distinguished and its abilities recognised. It therefore feels obligated to magnify and talk positively about the achievements of its members. Therefore, it is not easy to come to terms with the presence of a PWD in the family. Most parents, on getting a child with a disability undergo some of the following conditions:

1. *Shock* – when a child is expected, it is least envisaged that it will have a disability.

2. *Denial* – most of parents try to escape from reality by disbelieving the diagnosis.
3. *Anger* – a state of intense sadness and grieving (a very common reaction).
4. *Adaptation* – impulsive feelings subside and parents start building mechanisms for care of the child.
5. *Re-organisation* – a positive long term acceptance is finally developed.
6. *Overprotection* – over expressed protective feelings towards the child, wanting to protect it from any real or perceived danger or discomfort.

The Role of the Family

When there is a disability, the focus is on both the nucleus as well as the extended family. The family provides all the initial basic needs including security and the services of care giving. It also links the PWD to community service providers through mobility, communication, safety and all related interventions. The need to prepare the family unit well in order to capacitate it to provide this nearly lifelong psycho-social support therefore becomes very critical.

Family Responses: Personal Experience

It all looks like it happened yesterday. There is no doubt that there is power in the Blood of Jesus. I can also testify that there is power in the institution of the family. It derives from acceptance, support and resolving not to look back as a courageous soldier.

As a family we were both born of Anglican Christian parents. We grew up in the church and have undergone all the church rituals. We wedded in the church and have grown in the faith to become born again.

The Birth of Brian

It was all excitement for us when on 25 April 1987. Our child was born at the Mater Misericordiae Maternity Hospital in Nairobi, Kenya. As parents, we were very happy about this good news of a

bouncing first born baby boy whom we immediately named Brian. This excitement was jolted when we were informed that he had cataracts in both eyes. Our spirits were dampened. However, when we were informed that Brian would be operated on, we regained our happy spirits. We were assured that he would be able to see normally.

At this point in time, we did not know that it was only but the beginning of a long winding journey of struggle and frustration. We were discharged from the hospital with instructions that we should come to the eye clinic after one week. Celebrations went on as usual at home.

Cataracts in the Eyes

On the third day while at home, we noticed a little yellowish discharge from little Brian's eyes. This quickly developed into pus and by morning the following day, the eyes were completely glued and could not open. We moved fast and sought medical attention. Brian and the mother were immediately admitted at Kenyatta National Hospital for specialised medical attention.

Blood samples and specimens were taken for testing at the Kenya Medical Research Institute (KEMRI). Not much happened here. Hours of waiting for the results became days and eventually weeks. No test or analysis was ever carried out. They later explained that the reagents required to carry out the tests were so expensive that they could not be used on Brian alone! Therefore, they needed more time to accumulate more specimens from similar patients before proceeding with the test.

Kenyatta National Hospital

Meanwhile at the hospital, we had become a tool/specimen of learning and teaching for the Medical School of the University of Nairobi. Parties of professors and students of medicine would hold class sessions around Brian's bed, discussing the case in all the medical terms they knew best. They never involved us. They never consulted us nor gave any briefing on what they were up to. They

cared least to know whether or not we understood the English language and the medical jargon that they were using. It was just like they were in a laboratory and we were the specimen. This went on for about four weeks.

These four weeks were very agonising. The mother had hardly recovered from birth pains and the after effects of delivering. Her maternity leave was almost over. I was a Management Trainee and a Probationer at my new place of work. I visited them about three times a day. Therefore, balancing between my new job demands, trainee needs, house chores and visiting Brian were all very difficult challenges for me. In addition, I had to run after doctors to enquire about what they were doing concerning the case. But all the same, God gave me grace to manage all these. We kept on praying regularly.

Presbyterian Church of East Africa Eye Hospital

Where there is trouble, hopelessness and desperation all windows of opportunity never close. One female staff on the medical team saw our plight. She sneaked us out to the Presbyterian Church of East Africa (PCEA) Eye Hospital at Kikuyu on the out skirts of Nairobi. This hospital is sponsored by Christoffel Blinden Mission (CBM).

Here, we met Dr Wood (now retired), a renowned mentor and teacher. Within three days of admission, Dr Wood operated on Brian and fitted him with very heavy contact lenses to support his sight. We now graduated into a new phase of life of living with Brian with low vision in both eyes.

We now resigned back and started adjusting to living with Brian this way. Little did we know that there was much more awaiting us.

Apart from the visual challenges, Brian developed frequent convulsions. We again sought medical attention. After examination, he was put on a substance known as tegretal. With time these were controlled and this medication was eventually phased out.

Hearing Problems

We never realised that he had problems with hearing. Being our first born, reading and understanding the literature of 'Normal Child Development' was all 'Greek' to us. Up to age two, he still could not talk. He had only managed to pronounce "*bba*" and "*mma*." He could also manage to make some sounds as if he was clearing his throat or he had a throat irritation. These were his only attempts at talking.

He could only respond if you communicated to him while he is facing you. Should he give you his back then he would never respond to any communication. He could frog-march you to a point and show you what he wanted with some signs and sounds. Each one of us kept suspecting there was a problem but never dared share out. The wish was it should not be true that Brian cannot do...

None of us was courageous enough to take the bold step of seeking professional opinion. In any case we had no knowledge of where and how to start. We eventually shared this between ourselves. This only heightened our fears even more.

It was one afternoon when Brian was about two and a half years old. An auntie of his who is a medical nurse visited us. She noticed on trying some games with Brian that he could not respond to sounds! She shared this much with us and organised for us to see an ENT specialist. Brian was confirmed to have profound hearing loss. So far this was the most devastating news to receive.

Withdrawal and Denial

It drove us into withdrawal and denial. We could only find solace and refuge in each other. Friends and relatives started to wonder loudly what brought about all these. Some shunned us and severed any relationship with us completely. Life was never the same again. We lived only to ourselves in isolation. Life had to go on somehow!

We watched with jealousy as our peers started taking their children who were Brian's age mates to kindergartens. Where were we going to take Brian? He was developing into a 'social misfit' of some sort. He was aggressive and hyperactive. Other children

shunned him because of this. The residual sight was very useful to him as he could freely move around without a problem in familiar environments.

Deaf Blind

With time he rejected his spectacles. We were warned that he must wear them lest he loses the remaining vision. We were over protective and very sympathetic to him because they were thick and very heavy. Again we went back to see Dr Wood. When he learned that Brian also had hearing impairment, he referred us to the Kabarnet School for the Deafblind because Brian was Deafblind.

Bewilderment, shock and surprise were written all over our faces. I think that this was the worst news that we had so far received. We had never heard of Deafblindness leave alone the said school. We did not know where to start from. In this situation we took some time before regaining strength to move away from his desk at the clinic. Dr Wood noticed our bewilderment. He quickly directed us to see one Joseph Michael Morrissey, a Deaf Consultant with CBM. Their offices were situated on George Padmore Lane off Ngong Road in the Hurlingham area of Nairobi.

We reached Mr Morrissey as directed and were very well received. He saw our desperation, devastation and hopelessness. He was very helpful! We quickly bonded and he remains one of the most faithful friends we have ever come across in our lives. He remains connected to us and has been very supportive in every aspect.

Joseph Michael Morrissey

Morrissey played a bit with Brian and saw in Brian a very intelligent little boy. He told us as much. He said Brian did not stand to gain much by going to Kabarnet at that moment. He suggested that Brian goes to an ordinary Programme for the deaf with special attention from a teacher for the Deafblind. Further training for the specialised teacher would have to be done on the job.

This marked the beginning of another phase of challenges. I was immediately linked to one Ms Penny May of the Association of the Swedish Deafblind (FSDB/SHIA). This heralded a big turning point. She turned out to be equally good and has walked along with us ever since. Life has never been the same again. This was more than nineteen years ago.

Christian Life

As stated earlier, we are both Anglican Christians. Brian and his siblings went through all the church rituals. Brian underwent infant baptism, although confirmation was a big challenge. We did not know what to do. It had to wait for his two younger siblings! Were we going to allow them to undergo it before him?

We discussed the issue with our Vicar who had no idea what to do. She even said that she does not know how Bishop Peter Njoka who was going to officiate would receive it or react to it. We told her how desperate we were and the fact that our conscience was haunting us! Do it for Brian's siblings and not him! We agreed to work together.

We got an interpreter who helped Brian with learning the catechism through interpretation. The Vicar saw all these and was very encouraged. We told her to brief the Bishop appropriately and that the interpreter would be part of the exercise. She obliged, did the needful and the day came to pass to our satisfaction.

Going to Church

Brian loved accompanying us to church for worship. He could just sit there and watch with his little residual vision. Despite our exposure in sign language, interpreting for him, while at the same time participating in routine worship remained quite a challenge. Occasionally we could give this a try. The whole congregation would then focus just on us, wondering what we were doing. Many questions would be asked but irritably out of sympathy and at times pity. We felt completely out of place with no one to turn to.

Peer Pressure

With time we managed to link Brian with some older deaf young adults. We persuaded them to be taking Brian out to their places of worship. We got to know that there was a church service for the deaf at the PCEA St Andrews Church in Nairobi. It was organised every Sunday afternoon. We tried going there but again we felt out of place as it was for the deaf and interpreters.

With time we managed to link Brian with some older deaf young adults in that congregation. We persuaded them to be taking Brian with them whenever they went to worship at St Andrews church. We paid them some commission, bus fare, offertory, money for lunch and a little more for any arranged hike, site seeing or general socialisation. This appeared to be a major breakthrough for us despite the expenses involved. We took solace in the fact that since we spent a lot of money on Brian's siblings, this was not an extra burden.

Setbacks never lack! We learned that with the money we were giving out, sometimes they went to wrong social places such as drinking beer and smoking. Should Brian be exposed to such anti-social behaviour? Were we ready to meet the cost? We discontinued this and reverted to our routine.

Brian stayed away from peers for some time. However, again we then realised that he needed to be with his peers a lot. We managed to link him to The DOOR International that trains deaf pastors. The staff and trainees loved him. They allowed him to interact with them on daily basis.

However, he did not have enough communication skills to follow the routine training. For more complex text book material, he could be left out. He joined them mainly for social activities, practicals and outings. Otherwise he spent plenty of time in their offices helping with work. He blossomed very well and was very happy because of the many friends he made. After about 14 months, the organisation underwent some restructuring that resulted in Brian becoming redundant. We were back to square one.

Returning to Our Church Service

Now Brian shunned accompanying us to church. We tried but he completely refused. He liked to come with us only when we had a specific interpreter for him. This pained us a lot. With both of us in the PCC, we increasingly felt empty with Brian not able to accompany us to church. The mother was a Lay Reader while I participated in the choir and preaching.

Sign Language and All Saints Cathedral

As time went by, we walked into an opportunity. All Saints Cathedral launched sign language lessons. We took maximum advantage of this and all of us enrolled. We also managed to interest one of the members of our congregation to do the same with a view to providing this essential service to Brian. While attending these classes we learnt that the All Saints Cathedral has a church service for the deaf. We grabbed the opportunity and eventually moved from our congregation to the All Saints Cathedral where we are to date. Church going is now a very important routine activity for Brian and everybody in the family is very happy.

Social Support and the Creation of the Nairobi Parents

Solitude locks your potential and limits your horizon. Without exposure one is tempted to think and imagine that he is the only one with challenges and problems. In disability circles, lack of information and exposure can make you feel like the whole world is against you.

As parents of a child who is deafblind, we knew that we would sail in unfamiliar waters alone. The fears, challenges, loneliness, ridicule and stigma all appeared insurmountable.

Meeting Mr. Morrissey and Penny May Kamau of the Association of the Swedish Deafblind (FSDB/SHIA) along the way changed the course of things considerably. They both gave us the much needed reassurance and encouragement. Little did we know that there were other families facing similar if not parallel challenges!

Penny was working and interacting with other families in which Deafblind children or persons had been identified. The same way she talked to us, she also talked to these families independently. She informed us that there were other families. With time, the ice started melting and the message become “I would like you to meet this other family of ... who stay at ... and go to work in.... There are other families like this one of yours.”

With time she knew all our residences. She started encouraging us individually to get to know one another and to start meeting and sharing experiences. She suggested that we do this on one afternoon in one of the homes over a cup of tea.

First Meeting

Sometime in 1995, many of us convened in the house of Lauren and Anne Mkalla (the parents of Majala who is Deafblind). Only Penny May knew everybody. The rest of us were meeting for the first time.

Penny came along with Inger Rodbroe from the Netherlands and Marianne Riggio from the Hilton Perkins Programme for the Blind and Deafblind in Boston, Massachusetts. These were visiting consultants in the area of education for the Deafblind. We did introductions and got to know each other. Five families were present. We all revolved around our children – Majala, Shiko, Albert, Icharia and Brian.

It was all but a great joy to see one another. We shared experiences at great length. We marvelled at how much we had in common. We were also quick to see how much we could share or learn from each other if we agreed to work together. We at once resolved that we hold similar meetings on rotational basis in our houses every third Saturday of the month in the afternoon.

The response and commitment was overwhelming. I remember we were working in Meru town on the Eastern slopes of Mt Kenya – a distance of more than 250 km from Nairobi. That we religiously came for those meetings regularly and consistently is something

that I look back at and wonder where all the strength and determination came from.

The bond between the families grew from strength to strength. We quickly saw the need for having some educational services in Nairobi. Most of us needed a school near us as opposed to the only school that existed then in Kabarnet more than 300 km from Nairobi.

The Vision

There is strength in unity. There also is security in numbers. Both of these are expressions very true about our struggles. We started making monthly family contributions of Ksh 300 per family as a fund for some future project. With time this grew to over Ksh 27,000. We started from ideas, back to dreams and eventually concrete actions. We were determined to have a schooling programme in place for deafblind children. Our numbers swelled from an original five families to seven. The monthly meetings continued. We relocated back to Nairobi in August 1996.

St. Christopher's Deafblind Unit in Kilimani

An advertisement in one of the local dailies then caught the eye of one of our colleagues, Dr Mary Kimani. It was seeking out partnerships in Basic Education, Informal Education, and Education for the Girl Child. This was by Care International Kenya. Quick consultations, deliberations and discussions were done. We eventually dived into the murky waters and tried our luck. We successfully landed a funding that saw us start a schooling facility known as the St Christopher's Deafblind Unit in Kilimani, Nairobi. This was way back in 1997. It became and remains the only deafblind day care programme today.

This facility has grown and blossomed into what is today the Nairobi Deafblind Unit. It is under the Kilimani Integrated Programme for the visually impaired at the Kilimani Primary School on Argwings Kodhek Road, Nairobi. All the pioneer pupils have since out-grown it and graduated. Although it is now owned and managed by the Government of Kenya, it is a brain child and creation

of the Nairobi Parents of the Deafblind. We played a leading role in its conception.

We had many dreams. This schooling programme was only but one of them. Many for quite some time remained but that – dreams! Below are some of our dreams:

1. A resources centre to store and avail all necessary materials on deaf blindness.
2. A vocational school that can perfect skills learnt for production of marketable products that can generate sustainable income.
3. A home where people who are deafblind can live in case of loss of their parents.

How were we to fulfil these dreams? We needed to continuously work hard, probably get support from well wishers and with God being our helper through prayer.

The Brian Resource Centre

Creation of the Resource Centre

The above unfulfilled dreams continued to linger in our minds. We felt a lot more needed to be done. Brian's enormous potential might probably be never exploited fully. This led us into the creation and the formation of *Brian Resource Centre* as an important step towards responding to this great challenge. We hope to raise Brian to another level altogether in his life through this initiative.

We did not want to be selfish in all these endeavours. We are aware that there are many families in situations probably worse than Brian's. We would like to see Brian blossom alongside others, hence this great idea. We want to continue striving to develop and improve on it and yet remain steadfast and focused. We need all the support out there not only for Brian but also the other families and communities with deafblind children. We believe that the church can be one such friend to lean on.

Aims

Brian Resource Training Production and Dissemination Centre program for deafblind persons provides hands on training to deafblind persons. It also empowers them to be productive, useful and self-reliant members of the family. It was formed from a family's real life and practical experience in raising a child with a disability.

As a model resource centre, it aims at enabling deafblind persons to utilise their useful talents and potential, and build capacity to enable them attain a meaningful and quality life. Apart from empowering deafblind persons, the resource centre also encourages family and community involvement in its activities. The deafblind person is trained in relevant income generating activities alongside parents and key family members.

After careful and critical analysis of the limitations of deafblind persons, we have come up with a workable, viable and sustainable empowerment concept. Nobody knows the population of deafblind persons in Kenya. Even the latest Survey results released by the National Population Council of Kenya (May 2008) has no mention of deafblindness. Therefore, we can say with confidence that a large percentage of deafblind persons in Kenya have no access to any meaningful service. Even for the few who have access, they still have not reached a level where they are gainfully employed or able to effectively use their full potential. This scenario has resulted in the level of poverty and dependence among them and their families remaining extremely high.

Deafblind persons in Kenya and their families continue to suffer from isolation, stigma and rejection from the community at all levels.

In addition to lack of the socio-economic and educational empowerment, a majority of them literally live in abject poverty. Family members, in situations of heightened hopelessness and helplessness, have had their already precarious poverty situation aggravated with the burden of providing lifelong care to otherwise 'unproductive' deafblind persons. But who has prepared them for this?

The family as established has not been recognised as the main institution/centre for service provision. Existing institutions remain only but transitional. The family remains a permanent entity and destiny for the deafblind person. When the deafblind persons leave or graduate from these institutions, they are destined to go to the family. Here, they remain for the rest of their lives under the care of the family. Therefore, there exists a big gap in terms of an unprepared family that is expected to continue providing lifelong services to their deafblind person. Does anybody want to invest in the institution of the family?

With this program in place, the deafblind persons and their families are now empowered. They thus, become as resourceful as the other members of the community making them useful participants in sustainable poverty reduction initiatives. This in turn means they become self-reliant hence relieving their families of the burden of dependence and the worries of daily survival. They can earn income to contribute to the family's earnings and family members cease being burdened care givers and become income seekers and earners.

Lastly, as currently established, we believe that we are strategically positioned to address social stigma, isolation, discrimination and general negative attitude towards deafblind persons and their families. There are more avenues for increasing opportunities for quality life in the community for many more PWDs.

Lessons Learnt

There have been many great lessons learnt over time. There are many key areas that an average family whose member is disabled needs to be prepared and or supported. Probably the most important that should come first is obtaining the right information on disability in general and the specific disability in particular. This provides a strong basis for subsequent auxiliary services such as counselling for acceptance and predisposing oneself to deal with stigma. Involvement of the family in the total growth and development of the PWD at an early stage helps to retain useful numbers whose services will be required subsequently.

A united family forms a strong fortress against social prejudice and stigma. Then it can seek out other families and together, they can bond and start to speak in one voice in pursuit of specialised services. With more than one united family, the movement then becomes a group. As a group, members form a strong social support network where they can lean on each other. They can also seek out other groups and become strong national or international network.

Why Understanding Causes of Disability is Important

Understanding beliefs about the causes of disability is extremely important for the church and community for four reasons. First, it can influence the entry point for intervention. Second, it can be a rallying point for scriptural teaching. Third, it can provoke research initiatives towards addressing the underlying causes. Lastly, it can enable us to come to terms with the seriousness of stigma. Stigma weighs down a family. It is important to establish how the congregation and society in general within your jurisdiction view PWDs. This can help in determining whether to organise awareness campaigns targeting perception change.

Value of Investing in the Family

Investing in the family of the PWD is important in order to reduce the impact of the presence of disability in it. Each family situation is unique and therefore a critical analysis must be done of many variables. To begin with, good tact must be employed to establish rapport and build trust with all the concerned. You will need to identify the potential of the PWD, source support where it is lacking and prepare generally for lifetime care giving.

The family will also need strong cushioning against myths and stigma. It will be especially necessary to have the right information. Below are reasons why we need to invest in the family.

1. They are the first care givers, teachers, doctors, nurses and interveners in very many respects.

2. They link the PWDs to all social support networks including the religious leaders and all other service providers.
3. They form the lifelong social support fabric for the PWD.
4. The entire range of support services including spiritual to the PWD will be delivered through the family.
5. They are a reservoir of a wealth of knowledge about the PWD.
6. They are closed in themselves and shunned by most members of the community/congregation. They yearn for friendship, acceptance, association, involvement and inclusion in most social activities including the routines of the church.

Spiritual Guidance

Fortifying the family's faith using and supportive scripture is very important. Some helpful tips include looking for positives in apparently negative scriptures. Examples of apparent negative scriptures include, *invalid* in Healing at the pool (Jn 5:2-8; 5:14); "...*stop sinning or something worse may happen to you*" (Jn 9:2); *His disciples asked Him, Who sinned that this man was born blind?* (Lk 5:17-20) and Jesus heals a paralytic ...*when Jesus saw their faith, he said: friend your sins are forgiven.*

Building confidence and trust based on positive scripture citations is a strong starting point. Examples include *Neither this man nor his parents sinned, but...* (Jn 9:3); *the crippled woman healed* (Lk 13:10-17) and *a blind beggar receives his sight* (Lk 18:35-42). Families with PWDs need to be told the truth and in a professional manner so as to digest and build coping mechanisms.

Pastoral Care Ministry

Similarly, the church's pastoral care ministry or programme that is in place can do a lot for families with PWDs. Some of these are explained below.

Group Formation: A group of such families could be formed and supported to be strong and effective. Within the group, useful personnel with expertise in different fields could be identified and

nurtured to help in capacity building. Through this, issues and concerns of PWDs can be raised and planned for.

Expertise Identification: From the whole congregation, a reservoir of various professionals could be identified who could offer support services to families and groups within established church mechanisms. Such endeavours will generate expert knowledge, establish useful linkages with other professional service providers and built workable partnerships.

Information Documentation and Dissemination: relevant information will be collected and disseminated leading to effective exchange and flow of information. This can be coordinated by a pillar minister to reach both families and groups.

Sermons and Evangelising: The church should give periodic sermons on themes and topics that identify with and demystify disability. They should be preached well so as to touch and soothe not only families with PWDs but also the general congregation. PWDs should occasionally be given a chance to participate in routine worship and organise some special events with them at the centre.

Above all, society should embrace families with PWDs with clear, sincere, genuine Christian love radiating in as many spheres of church activities and initiatives as possible. A platform for self advocacy accorded from the church would go a long way to empower them and reduce stigma.

What is Expected of a Good Pastoral Care Minister?

Church workers should accept and view themselves as community workers providing pastoral care. There are many other community workers who are not church workers. Therefore, church workers should stand out as loving, caring, patient, understanding, encouraging, friendly, helpful, honest and exemplary. Families want someone they can identify with, a good listener, approachable and accessible to them as well as being not only flexible and firm but also focused.

Lastly, in a community where families with PWDs feel less valued, they are out to seek for more understanding. They would

therefore love a church minister who makes them feel important, respects them for whom they are and walks with them the difficult journey out of true Christian love.

Barriers and Challenges that May Face Church Workers

All church workers want to succeed in all their missions. Unfortunately, this may not always be the case. The entry point may have been very difficult or tricky, making it quite an uphill task to create the desired positive change. Deliberate obstacles could be placed in their way making delivery of service very difficult.

There may also be unresolved and unknown deep cited community variables that one may underestimate. However, there is no better way to failure than poor planning, execution and implementation. A willing and participative congregation can make a minister's work very easy and enjoyable.

Reasons for Lack of Support from Members

It is possible that members of the congregation may not support an initiative geared to supporting the cause of PWDs and their families. They may not have been well informed, adequately briefed, or appropriately involved in the various stages of planning to implementation. In this way, they may feel that they lack ownership.

It may also be possible that they lack adequate knowledge and skills appropriate for the task ahead. If the timing was wrong and there were other competing priorities that relegate the importance of this one, then it may not be supported. Lastly, there are social variables that can kill a very noble initiative. These include women not being recognised as service providers or some of the people you have involved not being acceptable to a section of the congregation or community.

Considerations When Working with the Community

There are a number of considerations when working with the community as discussed below.

Participation: Members work together by making collective decisions from the beginning and providing resources: time, money, facilities, materials and labour.

Gender Issues: Be particularly sensitive to gender. Take recognition of existing gender issues and influences. It will be important to know how this impacts on especially operational variables over and above group dynamics. As much as possible, promote the spirit of togetherness and collectiveness.

Partnership: Seek for similar groups, associations, organisations and initiatives which you can cooperate with to avoid monotony and duplication.

Networking: Share information with various organisations, groups and associations. This can include training, reports, case studies and education material.

Sustainability: Identify activities that can continue long after you have left the community. Build the capacity of the community to sustain their programme.

Possible Activities when Working with People with Disabilities in the Community

It is worth considering what kind of activities you want to engage the community in. The following are just but a few examples:

Awareness Raising: This involves giving information about the specific disability. Find out people's beliefs about disability, facilitate them to see the real facts and avoid antagonising or belittling their beliefs. Remember that all attitudes can be changed but over time.

Building Capacity: Train the family members of PWDs in skills that will help them cope with attitude and stigma, live with and manage the disability as a permanent condition, and finally build their spiritual capacity to withstand and cope with particularly stigma and social exclusion.

Counselling: Offer counselling services to all those affected to come to terms with the disability. Do this professionally from an informed point of view.

Facilitate the Congregation to Participate: This will help them to develop knowledge, better their understanding of disability, look for an entry point, win prestige and develop responsibility.

Needs Assessment: Identify the immediate critical individual and family needs and work out a strategy on how best to address them with the involvement of the congregation.

Resource Evaluation: Identify existing and readily available resources. Explore ways and means of mobilising them for optimal outcome for the benefit of all the members of the congregation. Solicit for what they have by encouraging giving and sharing in the spirit of Christian love and being ‘my brother’s keeper.’

Linking and Connecting: Identify what it is you may need to source from outside such as from neighbours, existing organisations or institutions and the logistics involved. Collectively work on strategies of how well to share locally and readily available resources. Go ahead and link the family to these outlets.

Plan of Action: Together with the family, try and come up with a work plan for functional rehabilitation.

Implementation, Monitoring and Evaluation: Once the programmes are running, monitor and evaluate them continuously. Also, review progress appropriately and make the necessary adjustments accordingly.

Weaning: This has to do with you determining when to hand over the family to an auxiliary you have prepared. This will give you time to take a break, allow the family to manage on their own and allow you to move on to another family or client.

Retrain: Train a key family member on how to train and involve others in order to build a formidable resource of trained personnel in the family.

Pillar Ministry Resource: Ask some of the family members you have prepared to help you with extending such similar services to other families in the congregation.

Results of a Successful Initiative: The community comprises several families. A sensitised family that has come to terms with their PWDs will feel more confident involving them in community

day to day activities. PWDs should be visibly noticeable in such activities as public functions, church organised hikes, worship rituals, community or small group fellowships and prayer meetings.

Emerging community initiatives like UN Disability Days, HIV & AIDS functions, drama, music and sport, as well as burials need to witness more involvement from PWDs. Tree planting, environmental management activities and major walks should subsequently see a lot more sensitised and empowered PWDs and their families.

The above efforts can lead to improved quality of life, a degree of independence, raised dignity and self esteem and economic empowerment. These could lead to social acceptance and positive attitude change.

Conclusion

Disability affects the family in many ways. Stigma and loss of esteem can really wear out the family. There is great need for the family to be well grounded emotionally and psychosocially to be able to live with stigma. Disability will not disappear from the family. Disability is expensive and as such commits family resources. If you undertook a comparative analysis between those families with disabilities and those without, there are certain expenses a family living with disability cannot avoid. The working hours expended in lifelong care giving as well as the opportunity cost of what else the family would have done with its gross resources had they not been directed to disability can make a huge difference.

My son Brian humbled me. He transformed me from what I was at the time he was born to what I am now. I have learnt a lot from him. My dear wife Catherine has endured many days of nearly single parenting our children as I struggle to serve out there. To Catherine and our children I extend my big thanks for the support, patience and understanding.

We have walked this long journey together with several other personalities and service providers in the area of education. Brian is now 21 (twenty one) years old. He has a brother and three sisters.

He has been in school all along. He has good basics of reading and writing. He has good rudiments of Sign Language. He knows some basics in carpentry and knitting. He is a computer wizard in his own right. He can manage a very wide range of computer activities and exercises including setting out and dismantling the computer.

He can do basic cookery and laundry. He has near complete independence in a familiar environment. However, the insecurity in the City has limited his independence and exposure. This is a major social and environmental draw back. Our biggest challenge right now is how to perfect his Sign Language expressive skill and improve on his English vocabulary. He has been at the Door International and the Emmanuel Church in Nairobi for this mission. He is also a good swimmer. Quite an amphibian in water! He is also a horse rider.

CHAPTER THIRTEEN

Disability and Sexuality

Salome Wairimu Muigai

Introduction

Discussing disability and sexuality in the African context comes with multiple challenges especially when one is asked to talk about both concepts. Disability is viewed with mythical rather than factual appreciation and sexuality is hardly discussed publicly, leave alone in the context of disability and to a lesser extent within the African Christian Church. In real terms, this is one area where actions speak louder than words.

In the majority of African cultures, disability is viewed as a curse to the extent that the family within which a person with disability is born experience rejection in the community. Families with disabled people tend to hide the ‘source of their shame’ from the eyes of the community from whom they seek acceptance. Even in the Social Sciences arena, we still come across such terms as “Rights of Persons with Disabilities” 60 years after the passing of Human Rights Convention. This is also true thirty years after Gender was introduced into our developmental vocabulary and every researcher learnt (some painfully) to give gender-disaggregated data in order to find acceptance and be considered politically correct. When social justice pushes society to acknowledge the needs of persons with disabilities, it becomes difficult to deal with these needs at the gender level also. You may all have come across washrooms labeled “Ladies,” “Gents”

and “Disabled.” The question remains: Are the disabled a third gender or a genderless group? If “Black” were to be substituted for “Disabled” it would certainly raise a public hue and cry.

Society has perfected the art of ignoring discourse on topics such as disability and sexuality until it has absolutely no choice but to take note. Put this also into a church context, and discussion on the two concepts becomes a “no-go zone.”

An American Disability Activist and author, Anne Finger, once said that sexuality is often the source of disabled people’s deepest oppression. “It is also often the source of our deepest pain.” (Anne Finger, quoted by Selina Bonney, 2004: 125)

Rule 9.2 of the UN Standard Rules for Equalization of Opportunities for People with Disabilities which deals with matters of families and personal integrity reads as follows:

People with disabilities must not be denied opportunity to experience their sexuality, have relationships and experience parenthood. People with disabilities must have the same access as others to Family Planning Methods as well as information *in accessible form* (italics mine) on the sexual functioning of their bodies. (United Nations, 1994. 9.2).

It is already evident that there is need to amend this article to include information on HIV & AIDS. In the past this critical human right has been denied to people with disabilities in a variety of ways as discussed below:

1. In traditional African cultures and in formal educational set-ups, children with disabilities and teenagers have been dressed in unattractive and asexual clothes, and denied relationships and sexuality education. They have also been placed in gender-segregated Special schools and institutions especially during Secondary School Education which coincides with their teenage years. Such Special schools often

- fail to facilitate co-educational activities that allow boys and girls to meet and socialise.
2. Through physical, attitudinal or societal barriers, disabled adult women have been treated like children, sterilized, prohibited from engaging in sexual activity and marriage, excluded from mainstream social and leisure activities.

The next section of this paper will discuss some of the key issues that are facing disabled people with regard to sexuality. This would be a very broad field so we shall give only a few examples.

Societal Perceptions

Society generally perceives the sexuality of a disabled person as repulsive. At the other extreme 'women and men of good will', including the Church and the majority of our parents, consider the disabled person to be without sexual feelings. In news items, the mass media as the mirror of the society usually portrays the disabled as recipients of charity. They are also normally portrayed as evil characters in the movies or tragic victims of illness or accidents. The reality of disabled people being parents involved in practical and empowering relationships and professions are rarely portrayed. It was a privilege to see women and men with disabilities on the catwalk during the Association of the Physically Disabled of Kenya's Golden Jubilee in 2009 in Nairobi.

Unfortunately, the portrayal of people with disabilities in the mass media and the persistent negative messages adversely influence our perceptions of ourselves, especially our self esteem, confidence and sense of belonging. All these affect our sexuality as well because they give the message that as men and women with disabilities, we do not measure-up to the standards that others set for us. Men perceive that they are not strong enough to be attractive while the women feel their disabled bodies (which are often thought of as deformed) could never be perfect and beautiful enough. For those seeking acceptance on multiple identities such disabled people who are gay or lesbians, the challenges are doubled or quadrupled and result in high levels of

rejection. Many disabled women have also experienced exclusion from the women's movement as women strive to shift from the traditional role of "care-givers". They have also been turned away by the disabled people's movement because it is still very patriarchal. It has been said that the man with disability takes out all his exclusion and discrimination frustrations on the woman with disability because the person who has been discriminated against often discriminates in turn. The marching-with- placards which make up the lot of the lesbians is more-often-than-not a 'no-go zone' for the woman with disability.

In the Christian Church, sex is only acceptable in marriage and for pro-creation. In the local context when a man with disability is well educated and has a job, the family, the Church and the community will encourage him to get married preferably to a non-disabled woman who will take care of him and their children. But for the woman with disability the story is different. The woman is supposed to be the care-giver and when she is seen as needing care herself, that can and does become a point of rejection by the man, his family and even the community at large. The Church has been slow in supporting the woman with disability to challenge such double standards. By and large the Church has treated sexuality in disability as a non-issue.

It is important to reiterate that sexuality is not just about sex. Sexuality is an expression of who I am: how I dress, relationships, confidence, self-image and making of choices. In other words, sexuality is part of our empowerment or lack of it. Morris (1989, 80) puts it this way:

"Many people assume we are asexual often in order to hide embarrassment about the seemingly incongruous idea that such 'abnormal' people can have 'normal' feelings and relationships."

I think it is the fear of sexuality making us equal and having no equal that tends to become threatening thus causing insecurity by removing us from our collective comfort zone.

Barriers Preventing Women and Men with Disabilities from Expressing Their Sexuality

There are many barriers towards the expression of sexuality for women and men with disabilities but this paper will only mention a few examples:

Attitudinal Barriers

One wise person said that there is only one disability and it is called a bad attitude. Shakespeare et al (1996) equated admitting that one is a disabled person with coming out of the closet as a gay, lesbian or bisexual. Selina Bonnie puts it this way:

I believe that even disabled people who are heterosexual go through a process of 'coming out' when they start to assert their sexuality.

(2004: 126)

Parental Overprotection

Parental overprotection is often cited as a hindrance to social experiences (Baker and Donnelly; 2001:74).

Parents tend to overprotect their disabled offspring by treating them as unable and childlike. The parents see this offspring as vulnerable and as one who can be taken advantage of. These loving parents find it hard to come to terms with the possibility that a member of the opposite sex could fall in love with this particular offspring and want to be in a meaningful relationship. It follows that the attitude of the rest of the society would similarly be negative. The combination of intrusive medical interventions (that treat our bodies as diseases to be cured or chronic diseases), societal obsession with perfect bodies, (as portrayed in advertisements) and the denial of our sexuality have led to many disabled people having negative body-image.

Environmental and Informational Barriers

In Africa, disabled people are still struggling for inclusion in basic services such as education, training, housing and health and access to facilities. It is only recently that people are raising questions as to why there is limited access for people with disabilities to social activities, leisure, relationships and sexuality.

Access to information is critical especially in this era of the Information Super Highway and it is important that information on sexuality should be available on this Highway in formats that are accessible to people with disabilities. Although electronic, audio and print media are considered the norm, the situation for disabled people is different.

Some of the social interactions such as flirting can be a great challenge to people with disabilities. Such acceptable flirting strategies as eye contact, winking and smiling may not be available to the visually impaired. Romantic music, poetry and common jokes need to be interpreted to reach a person with a hearing impairment. Body spasms caused by some disabilities can give negative connotations to the people who do not know about this.

Can There Be Greater Challenges?

If this chapter were to end here we would go away convinced beyond any reasonable doubt that society is unaware of our sexuality and we would believe that that is the worst that can happen to us. Fortunately, it does not end here and I would now like to discuss what happens when society chooses to recognise our sexuality.

An article from Plus News, Dar-es-Salaam says that “activists in Tanzania are becoming increasingly concerned about rising HIV & AIDS among mentally and physically disabled people, a group generally perceived to be at lower risk of contracting the virus.” “Infections among disabled women have shot up astonishingly in recent months and we attribute this to their physical inability to ward off sexual attackers,” said the doctor heading the section. “Some disabled women are lured into unprotected sex by partners who presume them to be in the low-risk group. Mentally sick women are

raped, and we only discover this when they are pregnant and brought to antenatal clinics by relations,” he added.

The doctor said that between two and four disabled pregnant women were found to be HIV-positive every month at the clinic, but noted that although many were raped, extreme poverty forced others to have sex as a means of economic survival.

A Disability Activist told a Conference in the same country that the perception that people with disabilities were ‘safe’ was encouraging unprotected sex with people who had physical or mental disabilities. He said that his country’s National HIV & AIDS Policy excluded people with disabilities and not only marginalizes them but also threatens their very existence. “What we have diagnosed is only the tip of the iceberg. Most handicapped people who are sexually abused never make it to the hospital because they are already stigmatised and handicapped by the very nature of being disabled, and when women conceive and contract HIV & AIDS, their social status (which wasn’t much to start with), becomes worse,” the doctor added.

Additional information shows that when the sexual abusers are members of the family who are meant to be protecting the victims, the families tended to be secretive about the cases in order to protect the abuser. In some cases fathers were found to be abusing their daughters as did brothers, cousins and neighbours. Some of the women, especially, were abused by teachers, pastors and priests, doctors and medical staff and even private and institutional drivers. The young boys were also found to be easy prey to sexual abuse at many levels. A female HIV & AIDS activist, Mpendwa Chihimba says,

This is a challenge to the government and society: to address the physiological and health needs of the disabled, or else their right to life will be perpetually under threat as a result of sexual exploitation and abuse.

A recent study in neighbouring Uganda on the knowledge and utilisation of reproductive health including Family Planning and HIV & AIDS by the disabled people shows that many of them, particularly the women, lack knowledge and access to such services in the country. Another report conducted by Disabled Women's Network and Resource Organisation states that many women with disabilities are vulnerable to unwanted pregnancies and HIV & AIDS mainly because of their gender and the nature of their disability. "While the physically disabled women cannot run away from their abusers, the deaf, dumb and blind cannot shout or protect themselves from their abusers," says the study.

Is Sexual Abuse an African Phenomenon?

Sexual abuse is a global problem. I started by highlighting the situation in the region because I focused on finding documentation on the subject in Africa because such literature is scarce. Cases from the developed world are better documented and the studies have been undertaken over a longer period of time. One School of the Deaf in the United States of America had men in their 40s and 60s seeking compensation because of sexual and physical abuses committed to them while they were school boys in the 1950s and 60s. A case in the Courts New York made headlines in 2002 where a woman of 44 years was being tried for defiling an 11-year-old blind boy. This woman was a Teacher Aid who worked in the school the boy was attending. Of course the revelations of sexual abuse within the American Catholic Church come to mind whenever this topic comes up. Some of the victims were youth with disabilities.

Finally, a woman with disability, in Australia, who lived with her elder sister, became pregnant. She tells her story in her words,

While my sister was still at work, my brother-in-law would come home early with an excuse of a headache, but instead he would force me to have sex with him. I was terrified, unable to defend myself against such a situation, helpless and everything just went blank. These happenings were going on for a year and it seemed

that I just could not do anything to help myself so I became submissive each time he came to me. Telling my sister about it was not my intention as I would never be believed and of course I would be creating a fuss and causing a rift in the home. No one knew of the horrible scene that was happening in the house until my pregnancy was discovered.I was asked a lot of questions which I did not answer truthfully, but one day I broke down and told them the entire story about my brother-in-law. They all blamed me. It must have been me who made him do such things to me. I was the one to blame. So for my sins I was put into hard labour....Then to add to my traumatic life, my baby was taken away from me after 3 days of being close together. To my knowledge my baby has been taken away overseas. I was seen as unfit mother due to my disability.

These few cases give us an idea of what can happen when the sexuality of disabled persons is not addressed openly. It creates a situation that encourages abuse.

Conclusion

Despite the challenges, difficulties, issues and implications explored in this chapter it is important to acknowledge that many disabled people enjoy loving, fulfilled and fun sex lives. Many are getting into long term relationships, becoming good parents and useful members of their communities. However these are ones who have been given the opportunity, space and support to enable them to grow and prosper. I conclude by inviting the Church to become partners in unveiling the Image of God that may have come in unexpected form. So did Christ of Old!

Disability, Society, and Theology

CHAPTER FOURTEEN

Gender and Disability Challenges Within the Church

Josephine Sinyo

Introduction

For me as a woman with a disability, the topic of gender and disability deals with the “life sentence” for my lot! Mark my words, I did not say death sentence, for that’s a dead end. A life sentence implies that we are alive yet trapped, judged and sentenced for being women with disabilities. This paper will discuss what has been described as the dilemma of difference by policy makers in gender and disability issues. It will emphasize that, whereas the relevant “difference” in the context of gender is largely one of attitudes; the “difference” in the context of disability has some foundation in reality. Much of course, depends on how this difference is viewed. If it is not something inherent but defined in relation to some privileged norm (egg “maleness” or “able bodiedness”), the problem is not difference *per se* but the privileged norm. A commentator stated that: “viewing disability as normal rather than deviant” would mean that workplaces and qualifications, community programmes and standards generally, would reflect the needs of persons with disability as well as the non-disabled majority. Therefore, this paper will not only discuss the usual gender disparity issues, but also the disability limiting challenges that confront persons with disabilities in relation to Gender.

Gender Analysis in Creation

During creation God created everything and stated that it was good. Strangely enough Adam was the only one of all other living creatures that God had created that was not good and God had to create a woman to be his helper. God further gave Adam strict instructions on what to eat and not to eat. God did not give such instructions to Eve. After failing to follow God's instructions Adam blamed Eve. Surely Adam was not good. Certainly God is all present, all knowing and all powerful. Yet, God went out of his way to ask Adam where he was after disobeying God's instructions. Of course Adam was hiding because he had not done a good thing. If anything, God knew where Adam was. This question was meant to determine Adam's position with God because he had been influenced and fallen to deception and lost authority just by compromising his stance. Indeed the emptiness that Adam experienced then is being manifested even today amongst our men. A male person struggles for identity as a "man" to the extent that, in this endeavour, some cling to the beer bottle, guns or abuse of women. In search for their manhood, some males have opted to become women! Only a man affirms a man; the male gender need to know and relate with God the Father and almighty now than ever before.

Essential Concepts in Gender And Development Women in Development (WID)

The Women in Development (WID) concept first manifested itself in the early 1970s as an approach to include women in development. Research and information collected through the UN Decade for Women (1975-85) highlighted the existing poverty and disadvantage of women and their invisibility in the development process. Different policy responses and interventions focused on women as a separate group, resulting in women's concerns being "added on" and peripheral to mainstream development efforts. WID policies and interventions have to a great extent concentrated on women's productive work. The failure to make an explicit link with their reproductive work often adds to women's workload. Focusing on

women in isolation means that unequal gender relations in various social and economic settings remain unaddressed.

Gender and Development (GAD)

The Gender and Development perspective emerged in the late 1980s as an alternative to the then prevailing Women in Development or WID approach. Unlike WID, which focused on women only, and called for their integration into development as producers and workers, GAD focuses on the interdependence of men and women in society and on the unequal relations of power between them. The GAD approach aims for a development process that transforms gender relations in order to enable women to participate on an equal basis with men in determining their common future. The GAD approach emphasizes the importance of women's collective organization for self employment.

Sex vs Gender

Sex refers to the *biological* differences between men and women, which are universal and do not change. **Gender** refers to *social* attributes that are learned or acquired during socialization as a member of a given community. Since these attributes are learned behaviours, they can and do change over time (with increasing rapidity as the rate of technological changes intensifies), and vary across cultures. *Gender* therefore refers to the socially given attributes, roles, activities, responsibilities, and needs connected to being men (masculine) and women (feminine) in a given society at a given time, and as a member of specific a community within that society. Women and men's gender identity determines how they are perceived and how they are expected to think and act. Furthermore, gender is one of the principal intersection variables (along with race and caste and class) deployed in the distribution of privilege, prestige, power and a range of social and economic resources.

It is worth noting that when the word "gender" was first used in this way, to signify social rather than grammatical difference, at the Institute for Development Studies at the University of Brighton,

in mid 1970s, the intention was to refine analysis of the differing impacts of development on different groups of women, as well as differences between women and men.

Gender Relations

Gender relations signify the social relationships between women and men. Gender relations are simultaneously relations of co-operation, connection and mutual support, and of conflict, separation and competition, of difference and inequality. Gender relations are concerned with how power is distributed between the sexes. They create and reproduce systemic differences in men and women's position in a given society. They define the ways in which responsibilities and claims are allocated and the way in which each is given a value. The term "gender relations" also refers to the relationships between people and their broader community, if these relationships vary with the sex of the people concerned. For example, the relationship between members of a village community and their local government entity is a gender relationship if men and women experience different benefits and controls from it.

Sexual Division of Labour

In all societies, tasks and responsibilities are typically undertaken by either women or men. This allocation of activities on the basis of sex is known as the sexual division of labour and is learned and clearly understood by all members of a given society, as are the circumstances under which the typical practices can be varied, and the limitations of this variation. Change usually takes place when the society is under some form of stress, for example when a community migrates to find work. The sexual division of labour is perhaps the most significant social structure governing gender relations. The expression "gender roles and responsibilities" is used synonymously with sexual division of labour.

Productive Work

Productive work refers to work that produces goods and services for exchange in the market place (for income). Both men and women contribute to family income with various forms of productive work, although men predominate in productive work, especially at the higher echelons of remuneration. Historically, in most societies, changes in economic structure, and hence in the structure of productive activities, have led to changes in the sexual division of labour and gender relations.

Reproductive Work

Reproductive work involves all the tasks associated with supporting and servicing the current and future workforce – those who undertake productive work. It includes but is not limited to childbearing and nurturing. It has increasingly been referred to as “social reproduction” to indicate the broader scope of the term than the activities associated with biological reproduction. Socially reproductive activities include childcare, food preparation, care for the sick, socialization of the young, attention to ritual and cultural activities through which the society’s work ethic is transmitted and the community sharing and support which is essential to the survival of economic stress. The fact that reproductive work is the essential basis of productive work is the principal argument for the economic importance of reproductive work, even though most of it is unpaid, and therefore unrecorded in national accounts. Women and girls are mainly responsible for this work, which is usually unpaid.

Gender Equity

Gender equity is concerned with the promotion of personal, social, cultural, political, and economic equality for all. The term emerged out of a growing recognition in society of pervasive gender inequities. Continuing traditions of stereotypical conceptions and discriminatory practices have resulted in the systemic devaluation of attitudes, activities and abilities attributed to and associated with girls and women. The negative consequences of stereotypical concep-

tions and discriminatory practices adversely affect males as well as females. However, in the short-term, greater emphasis in the gender equity initiatives is placed on improving conditions and attitudes as they affect girls and women. In the long-term these initiatives will also improve the situation for boys and men.

Gender Equality

In the context of international human rights, the legal concept of gender equality is enshrined in the 1948 Universal Declaration of Human Rights, as well as in the 1979 United Nations Convention on the Elimination of all forms of Discrimination Against Women. The Convention which has been ratified by 100 countries, states clearly and unequivocally that “discrimination against women violated the principles of equality of rights and respect for human dignity.” The governments of the world reaffirmed their commitment in 1995 to the “equal rights and inherent human dignity of all women and men” in the Beijing Declaration and Platform for Action from the United Nations Fourth World Conference for Women held in Beijing, China in 1995. The conference built on the perspective and strategies outlined at the previous United Nations conferences on Education (Jom, 1990) Environment (Rio de Janeiro 1992), Human Rights (Vienna, 1993), Population (Cairo 1994), and Social Development (Copenhagen, 1995), including the Convention on the Elimination of all Forms of Discrimination against Women (1979). Based on the principles of human rights and social justice, it clearly recognizes that gender equality and women’s empowerment are essential for addressing the central concerns of poverty and insecurity, and for achieving sustainable, people centred – development.

Parity

This is the recognition of full equality between women and men in all areas of life: national political, economic, social development.

Fair Representation

This is a central principle of democracy. Fair representation is about ensuring that women who make up half the Kenyan population have an equal voice in determining the way their society is governed which requires that women in large numbers must be present and participating at all levels and centres of power in their society.

Social Justice

Social justice is a commitment to policies, principles, and measures that bring about just and fair social arrangements. These measures and arrangements enable all people and communities to live up to their full human potential and to actively participate in and benefit from the social, economic, cultural and political life of the country. Affirmative action is a social justice measure that provides TEMPORARY mechanisms to redress what has been unfair and discriminatory so as to ensure gender parity. Affirmative action makes equality between men and women a political and social reality. It compensates for past and present discrimination, promotes equal opportunity and eliminates the effects of previous barriers that women had to contend with within a variety of spheres.

Gender Mainstreaming

Gender mainstreaming is a strategy for making women and men's concerns an important consideration in designing and implementing policies and programmes in political, economic and social spheres. The aim is to enable women and men to share equally to prevent inequality from being perpetuated. The most important requirement in gender mainstreaming is an enabling environment. This means the presence of political will, resources, administrative frameworks, and processes. It also includes having women in decision making positions and the support and involvement of civil society to promote gender parity, equity and equality.

Gender and Persons with Disabilities

Before moving on to an analysis of gender and disability, it is important to view the actual situation of persons with disability in light of the above statements. In most cultures persons with disabilities have been effectively excluded from the economic, social and political spheres of life throughout history. By and large, such exclusion has no rational grounding whatsoever and, rests on either naked prejudice or, perhaps worse popular and official indifference. Otherwise, a sharper focus on disability issues, paying attention to the rights of those directly affected and taking into account the diversity of their experience, will help achieve greater equality of rights and opportunities for persons with disability. This measure will go a long way in humanising the world, unlocking the puzzle in gender and disability, exposing the problem of the sidelined, and putting in place affirmative action to address the anomaly.

Women with Disability

Problems of persons with disabilities have been considered by the United Nations for many years including its International Year for Disabled Persons in 1981. Initial attention did not recognize difference between women and men, in disability. Many issues, like physical accessibility, are the same for both men and women with disabilities. But women with disabilities have known that many issues affect them differently and that discrimination occurs against women and against persons with disabilities. Undoubtedly, women with disabilities suffer double discrimination. It is evidenced that the first United Nations document that has been inclusive of the concerns of women with disabilities, was the Beijing Platform of action. Despite rain, inaccessibility of buildings and lack of political power, women with disabilities gained recognition of their rights and their concerns in the final documents of the Beijing Conference. The platform for action adopted on September 16, 1997 contains throughout its text specific recommendations about women with disabilities.

The disabled women in Beijing had shown that solidarity, preparation and hard word could make their issue one that the world would

take as its own. One of the great successes of Beijing was the way in which disability issues were woven throughout the twelve critical areas of concern and clear manner in which recommendations were made to Governments and the International Community. I wish to submit that, this high spirit of solidarity and articulation of issues of women with disability was historically repeated during the negotiations for the UN convention for persons with disability in which article 6 is conspicuously put for women with disability, and in addition, gender and disability concerns are captured throughout the entire instrument.

I will now highlight what I feel are the very crucial areas of concern that require consideration as we examine some of the strategies for redressing the imbalances that have existed for a long time impacting gender and disability within the church.

1. In relation to women and poverty, majority of women with disability are the poorest of the poor and live in object poverty.
2. Majority of the women with disabilities are illiterate and untrained. Little investment is made in us and therefore many of us lack confidence and self-esteem.
3. Regarding health, majority of women with disabilities are not valued and are seen as worthless and are therefore deprived of medical and health facilities.
4. Majority of women with disabilities succumb to the worst forms of violence against women. Yet society, church and family keep it undercover, a situation that perpetuates our de-humanisation.
5. The plight of women with disabilities in armed conflict situations is deplorable. They are amongst the most sidelined victims.
6. In relation to the economy, majority of women with disabilities do not live fulfilling lives as they are not economically endowed. The church treats them as objects of charity.

7. Turning to the issue of power and decision-making, the majority of women with disabilities have no credentials, no Godfathers, no connections and therefore are the powerless of the powerless in both the state and church.
8. Institutional mechanisms for the advancement of women abound in churches including many forms of women movements such as deaconesses, women guilds, merry go rounds to mention but a few. The irony of it all is that even here, these women do not partner with women with disability whom they most often than not they are marginalised.
9. Human Rights of women
10. Women and the media.
11. Women and the environment.
12. I submit that in order to address the concerns of a girl child with disability it is imperative that we unveil the “curtain mystery” around her: ordinarily, where there are resources in a family, investment in preference amongst the children would rank as follows for instance in education:
 - The able bodied boy
 - The able bodied girl
 - The disabled boy
 - The disabled girl is number four in attention and this scenario is condoned by the church
13. HIV & AIDS- Although this epidemic was declared a disaster almost 10years ago, both the society and the church have paid very little attention to reaching the persons with disabilities with information on HIV & AIDS because of the wrong perception that that they are asexual beings.
14. Another area of total neglect is marriage. Every day of the week churches celebrate weddings in thousands amongst the able bodied. Even the men with disabilities marry able-bodied women. The fate of majority of women with disabilities is that disabled women are single parents and unmarried. Women with disabilities are always considered

of a lesser value than the able-bodied women and are often blamed for their disability and are not considered beautiful or admirable and are assumed not able to perform domestic chores efficiently. The church is doing next to nothing on this issue.

As women with disabilities, we know the problems and we have in many different fora attempted to articulate them but the definition of clear and well thought out implementation mechanisms have been lacking. The negative attitudes towards women with disabilities by men and non-disabled women have aggravated the situation. This notwithstanding, we as women with disabilities have to take the initiative to create space of our own to discuss our issues. At the same time, we also need to critically analyze power relations amongst all the women across the board. It is our responsibility to change the status quo. The assumption that all women's needs are the same only serves to re-enforce the naivety that surrounds women's issues and in my view this is a fallacy.

Disability, Society, and Theology: Voices from Africa

CHAPTER FIFTEEN

Combating HIV & Aids among Persons with Disability: A Disability Perspective

Paul Chappell

Introduction

Without doubt, the HIV & AIDS pandemic is a serious global threat to humanity. It impacts not only on the health status of a country but also on its socio-economic and political development. The current burden of HIV & AIDS is being most felt on the African continent, in particular sub-Saharan Africa. The United Nations Joint Programme on HIV & AIDS (UNAIDS) recent statistics indicate that of the estimated 33.2 million adults and children who are infected with HIV & Aids worldwide, 22.5 million live in sub-Saharan Africa (UNAIDS, 2007). Coincidentally, South Africa now has the highest rate of infection globally with an estimated 5.5 million people living with HIV & AIDS (PLWA) (see Table 15.1).

Table 15.1: Top 5 African Countries by number of PLWA in Africa (end 2006)

Country	No. of PLWA
1. South Africa	5,500,000
2. Nigeria	2,900,000
3. Mozambique	1,800,000
4. Zimbabwe	1,700,000
5. Tanzania	1,400,000

HIV & AIDS has had particular impact on vulnerable populations, such as women and children. This is clearly evident within sub-Saharan Africa because nearly 90% of all HIV positive children reside there. Also, an estimated 61% of adults living with HIV & AIDS are women (UNAIDS, 2007). Despite the reported decline in new HIV & AIDS infections amongst young people, women between the ages of 15-24 years still have the highest rate of infection throughout the African continent (UNAIDS, 2007; Pettifor, 2004).

Interestingly, little is known about the impact of HIV & AIDS on persons with disabilities (PWDs) although they are one of the world's most vulnerable populations. The World Health Organisation (WHO) has estimated that the world population is around 600 million. Of these, one person in ten lives with a permanent physical, sensory, intellectual or mental disability (Helander, 1999). Although disability is often addressed exclusively as a medical concern, the greatest problems facing people with disability are social injustice, poverty, and denial of human rights.

A recent global HIV & Aids and disability survey conducted in 57 countries, found that the risk factors associated with disability are similar to those for HIV & AIDS (Groce, 2004). These were identified as poverty, social stigma, unemployment, poor access to education and healthcare. In view of the above, it can be noted that

PWDs are at equal, if not increased risk of contracting HIV & AIDS. Also, this is a problem that is still largely unrecognised by stakeholders in the HIV & AIDS and the disability advocacy communities.

So, why is it that PWDs continue to be overlooked when it comes to HIV & AIDS outreach? Furthermore, how can PWDs and society rise to the challenge of the HIV & AIDS pandemic? This Chapter sets out some of the extrinsic factors for this exclusion. It also discusses possible ways in which both the community and the church can contribute to the inclusion of disability in the prevention and management of HIV & AIDS.

Youth with Disabilities

Education plays a crucial role in the development of skills, knowledge and identity amongst children and adolescents. However, according to Groce (2004), youth with disabilities are often shut out of education for four reasons. First, they are not considered to be in need of education. Second, they are assumed to be a distraction in schools; third, they are deemed to be incapable of learning. Lastly, many schools are physically inaccessible to PWDs.

The Role of Education

Evidence of this exclusion can be found in South Africa where, according to the Department of Education (2001), only 20% of children with disabilities are in formal education. Because of the lack of education, literacy rates globally amongst PWDs have been recorded to be as low as 3%. At 1%, the rates are even lower amongst women with disabilities (The United Nations Children's Fund–UNICEF, 1999). This inevitably leads to youth with disabilities being unable to participate in the social and economic mainstream of society.

Kelly (2002) argues that education; in particular school education has a significant role in reducing the high prevalence rates of HIV & AIDS amongst the youth. For instance, in Zambia, Bankole et al. (2004) found the prevalence rate for HIV & AIDS decreased amongst 15-19 year old women with some education.

Similarly, Klepp et al. (1997) found out that the inclusion of HIV & AIDS education in the primary school curriculum in Tanzania resulted in later sexual debut among students.

HIV & AIDS Awareness

Outside of school, non-disabled youth are exposed to sex education and HIV & AIDS information from a range of sources. These include magazines, television, radio, newspapers and billboards. They also acquire information from talking with friends and family (Francis and Rimmensberger, 2005).

There are also organisations which provide innovative ways to stimulate discussions and complement HIV & AIDS prevention in schools and at home (Zisser and Francis, 2006). A good example is Lovelife, South Africa – a national HIV prevention programme for youth. It was launched in September 1999, by a consortium of leading South African public health organisations in partnership with other stakeholders.

Changes in youth culture have also influenced perceptions of youth identity and how they relate to issues surrounding sex and HIV & AIDS. Before, the youth of South Africa mobilised against political issues. For example, unlike in the past, a less politically focused youth culture has emerged with emphasis on music and sports icons, popular entertainment, brands and consumerism (Lovelife, 2004). Although some of these information sources can be misleading, popular youth culture plays a pivotal role in influencing youth's understanding of themselves, gender norms, sexual identity and their relationships with others.

The situation for youth with disabilities is very different from their non-disabled peers. For instance, youth with disabilities who do not attend school not only lose out on basic reading and writing skills but also on gaining vital knowledge about sexuality, reproductive health and HIV & AIDS. Where sex education is taught at home, youth with disabilities often receive little information (UNICEF, 1999). This is because it is believed that they do not need such knowledge or that they will become promiscuous.

Collins et al. (2001) found that youth with disabilities in school were less likely to receive science and health education. Also, they were often excluded from sex education classes. This lack of education has resulted in significantly lower rates of knowledge about HIV & AIDS prevention. For example, Yousafzai et al. (2004) conducted a comparative study on knowledge and perceptions of HIV & AIDS between disabled and non-disabled youths in Swaziland. The results revealed that in contrast to the non-disabled youth, those with disabilities lacked knowledge about HIV & AIDS and were misinformed about the modes of transmission of HIV & AIDS. Groce et al. (2005) noted a similar situation amongst the deaf population in Nigeria. They believed that HIV & AIDS can be prevented by washing hands and eating healthy food, and avoiding hugging, kissing or using dirty utensils.

On the contrary, Philander and Swartz (2006) in a key informant study amongst 15 people with visual impairments in South Africa found out that they had a good knowledge about how HIV & AIDS is transmitted. Nevertheless, the participants in the study reported that illiteracy and inadequate education were responsible for increased risky behaviour amongst PWDs.

Although there is evidence of the influence of a media driven youth culture on the development of young people's sexuality, little is known about how youth with disabilities relate to this culture or develop their sexual identity. According to Groce (2004) this social exclusion limits opportunities for youth with disabilities to set boundaries and ultimately lowers their sense of self-worth. This often compromises their ability to say no when coerced to have sex or experiment with drugs and ultimately increases their risk of HIV & AIDS infection.

HIV & AIDS and Orphans with Disabilities

Orphans are considered to be a vulnerable group. According to Nganwa et al. (2002) at least 4-5% of orphans have some type of disability; also least 30% of street children are also disabled. Children and adolescents with disabilities orphaned because of their parent's

HIV & AIDS related deaths often have to be cared for by overburdened caregivers who have other children to care for. Such is the case notwithstanding what their HIV & AIDS status is. Findings from the global study on HIV & AIDS and disability found that such orphans with disabilities were more likely to be malnourished, neglected, institutionalised or abused (Groce, 2004).

Disability, Sexuality and HIV & AIDS

There is a widespread belief that PWDs are perceived to be asexual (Shakespeare et al. 1996; Anderson and Kitchin, 2000). The myth that PWDs are asexual appears to be associated with two key lines of thinking. First, the sexual needs of people with physical disabilities are deemed to be either absent or subjugated because of actual or presumed sexual dysfunction. Hence, the general myth that gratification opportunities are limited. Second, although their sexual function is typically intact, individuals with intellectual disabilities are thought to have limited social judgment. Therefore, they are thought to lack the capacity to engage in responsible sexual relationships (Milligan and Neufeldt, 2001).

Sexual contact is the most prevalent cause of HIV & AIDS infection in Africa. Therefore, given the notion of asexuality among PWDs, they are presumed to be at very low risk of contracting the virus (Swartz et al. 2006). Consequently, sex education programs for PWDs are rare and very few HIV & AIDS educational campaigns target or include PWDs. Furthermore, HIV & AIDS advertisements on radio and television are inaccessible to groups such as the deaf and the blind (Groce et al. (2006). In addition, these campaigns are often perceived as confusing to those with intellectual disabilities, who find it difficult to understand such complex information (Robertson et al., 1991).

The lack of sex education and myths surrounding sexuality have had negative consequences PWDs. They therefore unknowingly put themselves at high risk of contracting HIV & AIDS. For instance, Jackson and Wallace (1999) found out that women with disabilities were less likely to get married and were more likely to have multiple

sexual partners than their non-disabled cohorts. Mulindwa (2006) in a study in Uganda used Sexually Transmitted Diseases (STDs) as a proxy for potential HIV & AIDS exposure. The findings show that 38% of women and 35% of men with disability reported having had an STD at one time.

Over the past two decades, there has also been increasing evidence that people with a severe mental illness are at higher risk of HIV & AIDS infection than the general population (Chaung and Atkinson, 1996; Sullivan et al. 1999). This is because mental illness often results in poor interpersonal relationships, impulsiveness and dependency on drugs or alcohol. Interestingly, there is a widespread belief in some African cultures that having sexual intercourse can cure mental illness. Equally, it is believed that if one does not have regular sexual intercourse, it could also lead to mental illness. People with mental illness are therefore encouraged to have sex without being properly informed about precautions. This inevitably results in high rates of unprotected sex with multiple partners and increased risk of HIV & AIDS infection (Sprick, 2005).

Many of these situations arise as a result of the low self-esteem PWDs experience and the need to fit in with peers within their community. For instance, given the importance placed in some African communities of bearing a child, some women with disabilities may practice unsafe sex in order to have a child (Smith et al., 2004).

‘Virgin Cleansing’

In certain communities in Africa and Asia, there is a widespread belief that an HIV & AIDS positive man can cleanse himself from the virus by having sexual intercourse with a virgin (Groce, 2005). This concept of ‘virgin cleansing’ combined with the myth of asexuality, has led to the rape of PWDs by non-disabled people desperate to rid themselves of the virus (Yousafzai et al., 2004). This has happened to female and male, children and adults with disabilities.

Another variant of this practice has been reported in West Africa whereby in order for widows to maintain inheritance they

must remarry. According to the World Bank (2003), this has led to widows who are HIV positive seeking out men who are deaf or intellectually disabled. They assume that since they cannot communicate or understand how HIV & AIDS is spread, they would be more willing to take a wife who is HIV positive.

Unfortunately, many health professionals still fail to address the issues of sexuality and disability. Swartz et al. (2006) suggest that this could be because they receive insufficient training in dealing with issues of sexuality in relation to disability. They are therefore apprehensive about raising the issue. This lack of knowledge and anxiety could be seen as a barrier by which PWDs are prevented from receiving adequate information relating to sex and HIV & AIDS. This notion was highlighted in a study conducted in Zambia, whereby women with disabilities reported having attracted a lot of negative attention from nurses whilst attending reproductive health services. This inevitably discouraged them from using such services (Smith et al. 2004).

Similarly, the disability movement has been slow to react to issues of sex and HIV & AIDS. Many disability support groups and disability advocates perceive the discourse on sex and sexuality as a taboo topic. They would rather focus their attention on other social-economic concerns. Shakespeare (2000) attributes this to the fact that within the realm of the social model, the private lives of PWDs were not seen as being equally worthy of concern. These, he argues seem secondary compared to addressing issues like disability oppression, poverty and social injustice. The disability movement has been instrumental in bringing about social change. In retrospect, if it had taken up the issue of sexuality among PWDs as a civil rights issue, perhaps they would be better informed about sexual identity and HIV & AIDS risk.

Gender, Disability and HIV & AIDS

Gronemeyer (2002, cited in Hanass-Hancock, 2008) argues that the modernisation of the African continent and the recent processes

of globalisation have created a perfect “climate” for the rapid spread of HIV & AIDS. Four factors are responsible for the rapid spread of HIV & AIDS (Whiteside & Sunter, 2000). These are, first, the construction of highways and streets that reach into every little village. Second, the migrant worker systems that keep spouses away from each other for long periods. These encourage multiple partnerships. Third, the destruction of subsistence lifestyle and lastly, the development of sex as an income

These socio-economic changes and the breakdown of traditional institutions in sub-Saharan Africa have left women in an underprivileged and susceptible situation with increasing burdens and responsibilities (Siberschmidt, 2003). Given the low status often attributed to women in many African societies, it is well documented that they are more prone to HIV & Aids infection than their male counterparts (UNAIDS, 2007). In some communities, women are even held responsible for spreading the HIV & AIDS virus. For instance, Ingstadt (1990) used the female anatomy as a point of reference in her HIV & AIDS study in Botswana. Participants described women as ‘dirty’ and potentially more prone to carrying the virus than men. Similar notions were also reported in South Africa where Leclerc-Madlala (1999) found that the theme of ‘dirty’ or ‘dangerous’ women played a major role in the cultural related understanding and spread of HIV & AIDS.

The situation for women with disabilities is even more difficult than for non-disabled women. Elwan (1999) argues that even if girls with disabilities were allowed to survive birth, they face immense discrimination within families. They also have less access to healthcare, education and employment opportunities. Besides, girls and women with disabilities are three times more likely to be raped than non-disabled women. These attacks are rarely reported to law enforcement authorities (Elwan, 1999; Groce, 2005).

There are several contributing factors for the increased vulnerability to rape amongst women with disabilities. For instance, many countries

have few legal consequences for abusers of PWDs. Moreover, police, judges and social workers often attribute accounts of rape of individuals with disability to 'confusion' or 'misunderstandings' (Groce and Trasi, 2004). Groce (2005) also discusses the problem of communication. Many police stations and courts are physically inaccessible, lack sign language interpreters, or provisions to explain proceedings in simpler terms for individuals with intellectual disabilities.

Having limited ability to report rape or any legal repercussions encourages an atmosphere for abuse and high risk of HIV & AIDS exposure amongst women with disabilities. In addition to the legal barriers, making the incident public would further stigmatise a family that is already regarded as inferior because of a disabled and 'worthless' family member (Rapuro, 1998). Sweeny (2004) reiterates this point in the following example in Kenya:

In the village of Kisayani, south-east Kenya, a local disabled woman was raped. The family did not press charges but merely asked for 'compensation' of some goats from the offender. When interviewed, the father of the family stated that they are poor and there is little else that can be done. Furthermore, as head of the house, it was his decision to ask for such compensation as the daughter is unable in any other way to make up for her disability and ever since she was a child he has had to put money into caring for her whilst she cannot do anything productive for the family (Sweeny, 2004).

Although women with disabilities are seen as potential sex partners, they are often perceived as unmarriageable and unable to bear children (Yousafzai and Edwards, 2004). This misconception, along with the limited education and employment opportunities, mean that women with disabilities are usually unable to negotiate safer sex. The following examples from Malawi reaffirm this position:

In Malawi, a woman attending a local community based rehabilitation (CBR) centre to have her wheelchair repaired said

that some men in her village thought that they were helping her by having sex with her. Although at first she did not realise what was happening, she tried to say no but was ignored and now tries to avoid this group of men. The other village women resent her because of this apparent sexual attention which she receives from the men in the village; as a result, they are not supporting her against the men. The village chief chooses to ignore the abuse because his son is one of the offending groups. No man will consider her as a marriage partner because of what has happened.

Another woman, who has a learning difficulty, came to the CBR centre with her mother. The mother has been worried about her daughter because her daughter had recently given birth to a premature baby in a pit latrine. The daughter did not understand what was happening and the baby did not survive. She would not talk about what happened but her mother suspects rape and feels powerless to protect her daughter (AIDS Action, 1997).

As a further consequence of the lack of education and employment, many women with disabilities are living in extreme poverty (UK Department for International Development–DFID, 2000). Women and girls with disabilities remain vulnerable to exploitation and continue to be excluded and unrecognised by major HIV & AIDS campaigns because of poverty and powerlessness.

Poverty, Disability and HIV & AIDS

Evidence suggests that poverty and economic uncertainty play a key role in HIV & AIDS transmission and progression of the virus (DFID, 2000). For instance, poverty is related to a lack of income and possible food insecurity. According to Elwan (1999) this is thought to increase sexual risk taking particularly among women who may engage in sex work to secure food for themselves and their children. In addition, malnutrition is known to weaken the immune system, which in turn may lead to greater risk of HIV & AIDS transmission in any unprotected sexual encounter.

A DFID report (2000) recognises that there is also a strong interaction between disability and poverty, often in a vicious cycle. For instance, poverty could be a cause of impairment resulting from inadequate nutrition, or it may cause disability through the refutation of employment or education. Poverty could therefore be seen as a complex struggle between impairment, oppression and marginalisation. The World Bank estimates that PWDs may account for one in five of the world's poorest (Elwan, 1999). Also, as noted by Wolfensohn (2002), 'unless disabled people are brought into the mainstream of development, it will be impossible to cut poverty by half by 2015' as projected.

The link between poverty and risk of HIV & AIDS for PWDs is highlighted in a study conducted in Rwanda and Uganda (Yousafzai and Edwards, 2004). A research with several focus groups with young people with various disabilities, established that many of the participants were unable to afford condoms, or pay for transport to travel to health and VCT centres. In addition, poverty resulting from the lack of education or employment made many PWDs vulnerable to sexual coercion and abusive relationships for gifts or money.

Stigma: A Common Identity?

It is well known that stigma drives the HIV & AIDS pandemic throughout Africa. Stigma involves the setting apart of individuals or groups through the attachment of heightened negative perceptions and social values. Link and Phelan (2001) describe stigma as a process that may occur at the individual level. It is also influenced by social processes related to assumptions, stereotypes, generalisations and labelling of people as falling into particular categories on the basis of association. In terms of HIV & AIDS, these social processes are linked to issues of morality. The virus is associated with 'bad' behaviour such as sexual misconduct and promiscuity, and consequently deemed as a punishment from God. Stigma therefore involves the social expression of negative attitudes and beliefs that contribute to processes of rejection, isolation, marginalisation and harm of others (Parker and Birdsall, 2005). The

fear of being 'trapped' by an unwanted disease prevents many people from coming forward to be tested for HIV & AIDS (Swartz et al. 2006). People fear isolation, prejudice and reduced socio-economic opportunities, and the risk of being labelled as immoral or promiscuous.

In this respect, HIV & AIDS and disability share a common adversary of stigmatisation. Just like those living with HIV & AIDS, PWDs are also feared and misunderstood. Furthermore, in many African communities disability is seen as a 'punishment for sin', a curse, or as a consequence of not fulfilling the dictates of ancestral rites. As a result, PWDs are often hidden away in some communities not only out of shame, but the fear of 'contaminating' other non-disabled individuals with an 'unwanted disease' (Chappell and Johannsmeier, 2007). Given these beliefs surrounding HIV & AIDS and disability, it could be argued that being disabled and having HIV & AIDS is a 'double stigmatisation'.

The disability rights movement has made progressive steps towards eradicating stigmatisation. These include shifting the debate on disability from an individual medical construct to the social and political barriers that prevent PWDs from participating as equals in their communities. For instance, Oliver (1993) defines disability as the loss or limitation of opportunities that prevents PWDs from participating equally in everyday life of the community due to physical and social barriers.

Likewise, HIV & AIDS activists have taken a similar stance in an attempt to prove that those living with HIV & AIDS are not dangerous or inferior.

Considering these similarities, is it possible for the disability movement to work alongside HIV & AIDS activists? Some may argue against this possibility for one reason. In most societies, people living with HIV & AIDS (PLWA) are not classified as 'disabled' until their CD4 count is low and they are very sick. In view of this, some PWDs may worry that being identified as allies of PLWA may push them back into the realm of the medical model from which they have worked so hard to remove themselves (Tataryn, 2005).

Shakespeare et al. (1996) contend however, that the disability movement could learn from the 'professionalism, treatment, activism and resources of the HIV & AIDS lobby'. The disability movement could certainly benefit from the high socio-political profile and relatively well financed nature of HIV & AIDS activism.

Then again, PWDs are not commonly presented in a reassuring manner to the public as key role models for those living with HIV & AIDS. According to Tataryn (2005), PLWA are often reluctant to identify with a group that has historically been defined as ill, dependent and vulnerable. This point is further reiterated in national HIV & AIDS campaigns, which lack any sign of PWDs as positive role models. Swartz et al. (2006) highlight this position in their analysis of Lovelife in South Africa. They found that Lovelife's website and literature contain many images of young, attractive men and women with no obvious disability.

Despite the differences between the disability and HIV & AIDS activists, Tataryn (2005) strongly believes that an alliance between the two is essential if the underlying stigma associated with HIV & AIDS is to be truly decreased worldwide. Whatever the answer is to the question of cooperation between HIV & AIDS and disability activists, the fact still remains that PWDs are at great risk of HIV & AIDS. The interweaving relationship between stigmatised aspects of HIV & AIDS and stigmatised aspects of disability needs further investigation.

Issues of Accessibility

The inequities faced by PWDs are not just limited to poor education and employment opportunities, but also access to healthcare. Groce et al. (2006) observes that in many countries, HIV & AIDS testing centres and clinics are physically inaccessible with many having narrow doors and no ramps. Many testing centres also lack sign language interpreters, which raises issues of confidentiality for those who are deaf. Besides, as mentioned earlier, health workers have a negative attitude towards dealing with sexual issues that affect PWDs. Given this equation, it would suggest that many PWDs are not

reached by HIV & AIDS messages and are unaware of the symptoms and implications of the virus. This is confirmed by anecdotal evidence from many countries, which report about PWDs coming to clinics with full-blown HIV & AIDS when it is late (Groce, 2005).

Many African countries are still unable to access vital antiretroviral medication (ARVs). According to UNAIDS (2007), approximately 230,000 HIV & AIDS-infected individuals in sub-Saharan Africa were receiving ARV treatment by the end of 2006. Despite this figure, a further 540,000 were sick with HIV & AIDS but did not receive ARV treatment. Combined with the scarcity of access to ARVs and the lack of sensitivity to human rights, many countries prioritise access to treatment on terms of 'quality of life' or 'contribution to society' (Groce, 2005). As PWDs are often viewed from the medical model, they are perceived as having a lower quality of life and are therefore placed at the bottom of the list for ARV treatment.

HIV & AIDS as a Cause of Disability

The undeterred nature of the HIV & AIDS virus has led to numerous health conditions and impairments (Swartz et al., 2006). These include sensory impairments such as *gonococcal keratoconjunctivitis* (Lau et al., 1990) and some cognitive impairment (Becker et al. 2004). Nganwa et al. (2002) estimates that a third of PLWA develop some form of disability(s) after a short time. This situation raises contested questions surrounding the issue of HIV & AIDS status and HIV & AIDS illness when decisions are made about the provision of social security grants for PWDs.

Reasons by which decisions are made for the award of disability grants are not consistent in many countries, especially in relation to HIV & AIDS status. Swartz et al. (2006) point out that decisions to award grants are often based on activity limitations as a result of HIV & Aids-related illnesses. In some cases, decisions are based on CD4 counts. Basing the decision on the CD4 count is complicated, especially in view of the provision of ARVs. For example, if a person

takes ARVs, they may recover sufficiently enough to be able to work. However, given the stigma of HIV & AIDS and high unemployment rates, the person may not get a job. Theoretically, this person is also no longer eligible for a disability grant. This undoubtedly has negative consequences upon their family and their health and could even discourage a person from adhering to ARV treatment (Swartz et al., 2006).

Rising to the Challenge of Disability and HIV & AIDS

HIV & AIDS is a basic human rights and public health issue. Therefore, as stated by Groce et al. (2006 p.4), ‘the inclusion of individuals with disability in HIV & AIDS outreach efforts simply cannot wait until all other groups in the population are addressed.’ In view of this, effective strategies need to be established to encourage both the church and society to rise to the challenge of disability and HIV & AIDS. One such method is the practice of Community Based Rehabilitation (CBR).

Role of Community Based Rehabilitation

Over the past three decades, CBR has emerged as an effective method of providing rehabilitation services to PWDs and their families. Although its implementation differs from country to country, there is a general consensus around its definition. According to the ILO,¹ UNESCO² and WHO³ Joint Position Paper (2004: 2), CBR is defined as ‘a strategy within a general community development for the rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of all PWDs’.

The rhetoric of CBR places equal emphasis on social inclusion, equality and socio-economic development as well as rehabilitation of all PWDs. CBR can be seen as an effective strategy that raises the profile of disability and nurtures a more positive community

¹International Labour Organisation.

²United Nations Educational, Scientific and Cultural Organisation.

³World Health Organisation.

response. The focus on social inclusion and equalisation of opportunities provides valuable lessons which could be used for the prevention and management of HIV & AIDS.

Nganwa et al. (2002) argue that CBR could provide a useful entry point by which PWDs can access HIV & AIDS programmes. Due to the holistic nature of CBR, its primary role is dealing with the root causes that make PWDs vulnerable to HIV & Aids infection. Involvement levels in CBR can be classified into three distinctive levels of intervention as shown in Figure 15.1.

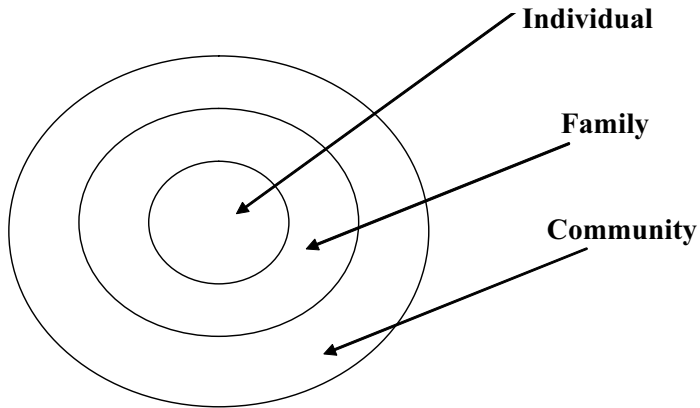


Fig.15.1: Levels of Involvement in CBR

(a) Individual Level

According to the UN Standard Rules for the Equalisation of Opportunities for PWDs

PWDs must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. PWDs must have the same access as others to family planning methods, as well as to information in accessible form on the sexual functioning of their bodies (UN, 1994, Rule 9.2).

In recognition of this article, children and adults with disabilities need to be taught about issues of sex and sexuality, including HIV & AIDS. In doing so, PWDs will become aware of their own bodies and emotions related to their sexual identity. Life skills training on topics like assertiveness, self-esteem and body image should also be given in an attempt to help PWDs develop positive identity and also enable them to make responsible, informed choices.

(b) Family Level

Just like PWDs need to be informed about sexuality, families need to recognise that children with disabilities will one day become adults with sexual desires. Therefore, according to Nganwa et al. (2002) families of children and adults with disabilities must be helped to raise them to be confident and learn to abstain or refuse unsafe sex. As such, CBR can be a vehicle for sex and HIV & AIDS information to PWDs and their families.

(c) Community Level

With the advent of the UN Convention for the Rights of PWDs (2006), countries need to be challenged on the involvement of PWDs in all community issues. These include access to education, employment, health services and particularly access to HIV & AIDS services. Such services must therefore consider issues of disability in their prevention campaigns and awareness raising programmes. Leaflets should be developed in Braille, posters should include sign language, HIV & AIDS testing centres should be physically accessible and community members should participate in promoting and sharing the information appropriately. Groce et al. (2006) have developed a framework depicting various types of interventions for the inclusion of disabled people in HIV & Aids services (see Table 15.2) as a guide for local communities.

Table 15.2: Framework for inclusion of disability in HIV & AIDS services (Adapted from Groce et al., 2006)

Strategy	Level of Intervention	Suggested Activities
Type I	PWDs reached by same HIV & AIDS services just like the general public.	▪ Depict individuals with visible disability (i.e. wheelchair user, or a blind person with cane) in HIV & AIDS posters & billboards. ▪ Include examples of PWDs in HIV & AIDS material. ▪ Moving HIV & AIDS education, testing and service delivery to accessible places.
Type II	Adaptations are made to HIV & AIDS services to ensure PWDs are included as part of the general public.	▪ HIV & AIDS public service announcements adapted for the deaf (i.e. use of sign language interpreters). ▪ Make HIV & AIDS material available for the blind in inexpensive tape cassettes or CDs. ▪ Include topic of disability in curriculum for training HIV & AIDS counsellors. ▪ Train individuals with disability to be HIV & AIDS counsellors for whole community.
Type III	Disability-specific adaptations made to existing material and new material developed to reach PWDs outside the limits of the general public.	▪ Train HIV & AIDS educators in specific disabled populations (e.g. intellectual disability). ▪ Work in collaboration with local disabled people's organisations to reach PWDs outside the limits of the general public.

Table 15.2 clearly sets out ways in which disability can be included in HIV & AIDS programmes. In conjunction with the suggested interventions, it is important that on-going monitoring and evaluation takes place to ensure that first, many PWDs are reached. Second, that the information is relevant and clear and third, that PWDs are seen as active participants in the service and not just the recipients.

The Church's Response

Churches are grounded in communities. It is within these communities that life must be sustained and experienced to the full. In this lies their strength and credibility to act effectively in response to the impact and challenges presented by the twin issues of disability and

the HIV & AIDS pandemic. According to Pillay (2003), it is within the space of the local church where people gather voluntarily that the communal spirit must be rediscovered, reclaimed and nurtured.

Many churches in various communities engage in a lot of caring work and have regular awareness workshops on HIV & AIDS and its impact on the lives of those affected and infected. The Church's response of care, compassion, embrace and service is vital in terms of responding appropriately to the pandemic. It is indeed part of what the church ought to do. Take for example the biblical command of caring for orphans and widows.⁴ Many Christian organisations have set up outreach programmes for children orphaned by HIV & AIDS. For instance, Hands at Work in Africa (2008) developed the Masoyi Community Intervention Model in an attempt to address the growing problem of orphans. The organisation works in several African countries including the Democratic Republic of Congo, Mozambique, Nigeria, South Africa, Swaziland, and Zambia. This model takes a holistic approach through ensuring orphans are not only cared for in a home environment, but also receive continuous education, healthcare and spiritual support. Interestingly, in reviewing their website, no mention is made of services to children with disabilities orphaned by HIV & AIDS. This continues to be an area of great need.

The physical, emotional and spiritual care for persons infected and affected by HIV & AIDS, together with awareness campaigns and workshops have contributed toward "breaking the silence" and reducing discrimination and stigmatisation (Parker and Birdsall, 2005). Despite this, Pillay (2003) notes that there is still a deafening silence from some churches who believe that the disease is "out there" while others adopt a judgmental approach believing that HIV & AIDS and disability result from God's punishment for sinful behaviour. Not only does this perpetuate the continual marginalisation of PWDs, but it also creates the notion that the church is uncaring and inhumane. In order to counteract this view, the Church should develop guidelines to assist church leaders in appropriate ways of approaching disability and how to respond when people disclose

their HIV positive status. Furthermore, PWDs should be appointed to positions of leadership within the church. In acknowledgement of the popular phrase ‘nothing about us, without us’, PWDs in positions of leadership could have an influential role in terms of developing and monitoring the church’s response to the issue of HIV & AIDS and disability.

According to Pillay (2003), a shift towards a proactive phase is imperative if the church hopes to respond adequately and responsibly to a disease which impacts on all of humanity. Clearly the church as a whole needs to be involved at every level, engaging with government, NGOs, other faith communities and other church denominations in a collaborative effort to respond to HIV & AIDS. The Church should engage in appropriate moral discourses and implementing both proactive and reactive measures.

Conclusion

In the preamble, I noted that the HIV & Aids pandemic is one of the global concerns that affect all humanity. Through the continual subjection to social and attitudinal barriers, PWDs are put at increased risk of HIV & AIDS infection. In addition, certain sub-groups within the disability population are at increased risk of HIV & AIDS infection because they lack information and are powerless within the social stratum. Therefore, PWDs face stigma and isolation just like those living with HIV & AIDS.

The issue of asexuality is one of grave concern and could be noted as one of the driving forces towards the increased risk of HIV & AIDS infection amongst PWDs. Until PWDs are recognised as sexual beings, capable of love and engaging in sexual relations, they will continue to be overlooked in HIV & AIDS services and prone to abuse and marginalisation.

Embracing disability as a human rights issue is of utmost importance if we want to see the social inclusion and equal participation of PWDs in HIV & AIDS services. This means engaging with PWDs at the community level. The church is very

much part of the community and to date, it has been mostly reactive to the HIV & AIDS pandemic. Although the provision of physical, emotional and spiritual care is important, a more proactive approach is required if the church is to engage more meaningfully with PWDs. For instance, the church could succeed in their task of supporting PWDs and their families more effectively if they developed a tri-alliance with CBR projects and HIV & AIDS programmes. CBR projects can provide and facilitate the expertise needed to communicate better with PWDs. HIV & AIDS programmes could also help CBR projects and the church address issues of sexual equality and abuse amongst PWDs.

The community at large and PWDs have a moral responsibility to raise awareness of HIV & AIDS amongst PWDs and reduce the incidences of stigmatisation and marginalisation. As articulated in the Integrated National Disability Strategy of South Africa 'among the yardsticks by which to measure a society's respect for human rights, to evaluate the level of its maturity and its generosity of spirit, is by looking at the status that it accords to those members of society who are most vulnerable, disabled people, the senior citizens and its children' (ODP, 1997).

CHAPTER SIXTEEN

Persons with Disabilities and Psychological Perspectives

Ndung'u J.B. Ikenye

Introduction

There is relationship between the physical environment, body experiences and psychological processes of all persons. Basic humanness involves the body, mind, intimate relationships with others, the natural environment, institutions, and with God, our Creator. Disability affects the whole person, those related to the person, and the community. The quality of life and relationships are not affected by disability as long as such disability is integrated into the overall functioning of a person-the body, mind, relationships, systems of interactions and their quality, residential arrangements, and types of foods eaten.

The psychological perspective discussed in this chapter emphasizes that all these multiple levels of functioning have psychological dynamics. Our focus is the psychological processes and dynamics in relation to the disabled persons and those who live and work with them. One of our goals in this chapter is to increase awareness of the psychological dynamics involved in the lives of disabled persons and persons in their community and family. I am convinced that the more information and awareness we have on the psychological experience of disabled persons, the more we can enter into their world of reference, feelings (empathy) and their wholistic

experience (interpathy). Such awareness will show itself in the way we love, work, relate and live with disabled persons.

Definition of Terms

Three different terms are used by The World Health Organization (WHO) to define a disability. It is a “permanent condition of limitation in the ability to perform essential tasks.”¹ The three commonly used terms are impairment, disability and handicap.

Psychology

The interest of psychology is to describe the causes and effects of the limitations of psychological functioning of disabled persons. The second interest is to consider counseling as a tool of addressing the emotional wounds or pain and suffering. This chapter will focus on the psychological causes, effects, and how we treat disabled persons, their families and communities with the goal of accepting and living with disability in practical ways. For the disabled person, this chapter will also focus on psychological ways and means of accepting and living with disability. For those living and relating with the disabled person, this chapter will focus on the psychological systems of care.

Images of Disabled Persons, Family and Society

In 1988, a member of the parish I was serving as a priest appeared in the *Daily Nation* and *The Standard* newspapers and later on *Kenya Broadcasting Corporation* (KBC) TV for having hidden their disabled daughter for 18 years. She suffered from severe mental disability with learning and communication disorders. Her borderline intellectual functioning made her different from her other two sisters and brother. Nevertheless, this girl was physically attractive. In this chapter, we will keep her image as a person who brought shame and guilt to the family leading them to hide her in the inner room of the house and was never taken to social occasions, or to school. Her

¹*Dictionary of Pastoral Care and Counseling*, S.V., “Handicap and Disability.”

disability affected relationships in the family as they kept her presence secret from others. As plaque in the arteries restricts blood flow, so do the family secrets limits free communication thus brings division, estrangement, distortions, anxiety, and encourages false companionships.

The second image is of a man in the same parish, whom I met when I got to the parish in 1981. He suffered from a mild mental retardation; he never worked but lived with his father. His developmental disability was accepted by his family who valued him and treated him with respect. I was told that at some point, he was married and out of that relationship, two daughters were born. When I met him, his wife had already left him. The father of this man brought him and the girls to church every Sunday. We shall keep this image, of a disabled man, who was accepted and supported by his family.

Both these persons had intellectual disabilities that affected their linguistic processing, attention spans and resulted in deficits in social skills. The society and families have their own psychological processes and dynamics, defining what is possible and what is not. Society and families use these processes and dynamics in judging and dealing with persons like these with mild, moderate, severe, or profound mental disabilities and personality disorders. Disabled persons face either rejection and are not given the opportunities of being, or are accepted and supported to live adequately. Psychology of optimal and pathological functioning in individuals, family and society is defined by the society itself. These two images concur with Diane Driedger and Susan Gray who wrote that, "having a disability is no more a tragedy than having green eyes, what is a tragedy is the lack of sensitivity, awareness and knowledge that disabled women encounter, that the physical, psychological and social barriers that result."²

²Diane Driedger and Susan Grey, Eds. *Imprinting our Image*, (1992), 11.

With these two images, let me define the three terms used to describe mental disability from a psychological perspective. Impairment is a loss or abnormality with psychological causes or effects. This impairment causes functional limitations of comprehension, retention and recall, thus limiting mental capacities. One of the issues raised by clinical psychology here are the processes of mental impairment that are brought into the body, and from the body to the mind. The psychological impairments from the mind to the body are called psychosomatic illnesses.

The term mental disability is used to refer to the limitation as restriction and inability, mentally to perform psychological activity within a range considered normal for a human being. The limitation of the psychological apparatus, as a mental disability also means disturbances in task performance, skill and behavior. In a mentally disabled person, the fine motor skills as mental skills are derailed in one way or in multiple ways.

The term mentally disabled is the particular disadvantage resulting from impairment of the mind contents and structures. The interest of psychology here is the psychological effects that come with the disability. Psychological counseling will work on normalizing disability. Counseling will work toward empowering the disabled person to live a normal life of fulfillment and satisfaction in spite of disability. In discussing these three terms from a psychological perspective, one needs to be aware that “impairment is the cause, disability is what a person cannot do, and handicap is the social barrier, (psychological) attitude, or condition that restricts participation.”³ All three aspects of psychological disability have a loss of function.

One of the important principles in psychology is overdetermination or multidetermination. In our discussion, we shall come to realize that there are multiple causes and effects of disability. It is important to avoid simplistic answers to complex situations in discussing, caring, living and working with disabled persons.

³Ibid.

Another principle from clinical psychology is to understand that in mental disability, like all other forms of disability, there is a loss of function. Any loss leads to bereavement and grief. Disabled persons have to be counseled and empowered to “work through” and mourn losses by going through the stages of grief (is this the case with all disabled people, whether they were born with or acquired disability in later life?). Kubler-Ross suggested that there are stages that persons dealing with loss have to pass through in the grief work.⁴ These stages are denial and isolation, anger, bargaining, depression, acceptance and hope. Counselors have to help the disabled person and family to do this grief work.

Metapsychology as a Scientific Instrument of Inquiry and Intervention from the Beginning

The complexity of the human document, that consists of the body (physical systems), mind (thinking systems), relationships (relational systems), emotions (feeling systems), and participation experience (participatory systems) made Sigmund Freud to begin a hermeneutic science of understanding and intervening in the mind.⁵ This metaphor of a human document is discussed in detail by Charles V. Gerkin.⁶ In developing a psychology of disability, the complexity of the human document must remain in focus. The systems of relationship between the body, mind, and relationships with others are born from early life experiences in immediate families, society and culture with its core value and value system. The bedrock of all these systems in a person is the personality with its traits and character. All these aspects of

⁴Elizabeth Kubler-Ross, *On Death and Dying*, (New York: Macmillan Publishing Co., Inc., 1969), 38-156.

⁵Sigmund Freud, *Introductory Lectures on Psycho-Analysis*, Translated and Edited by James Strachey, with a Biographical Introduction by Peter Gay, Standard Edition, (New York: W.W. Norton & Company), 1966, 338.

⁶Charles V. Gerkin, *The Living Human Document*, (Nashville, Abingdon Press, 1984.), 37-54.

being a person play a major role in the life of a disabled person and those who relate to him or her, throughout the life cycle.

The intrigues of metapsychology of the psychoanalytic science and discipline are grounded in observable and testable human phenomena. In developmental psychology, Freud saw systems of understanding the psychologically internal (latent material) in terms of what is felt, thought, behaved out, and affecting relational systems (manifest material). In dealing with the nature of psychoneurosis and its cure, Freud developed theories of “conflict and compromise, of anxiety, resistance and defense, transference and countertransference... as theories of structure (and content) and functioning (malfunctioning) of the mind.”⁷ From the beginning, we need to be aware of the fact that, the psychological perspective has its holistic understanding and approaches to the conditions of the human document. The psychological perspective seeks to understand the physicality in relation to other parts of being such as psychosexual stages, behavioral systems and their meaning, sense of self and identity, feelings and emotions, effects to the ego (reality) and superego (conscience) development, cognitive- thinking systems and gender development, relational states, society and its effects to personality development, and participatory reality. The central idea is that there is “Wholistic and Holistic” health against mental and emotional pain and distress. This backdrop informs the etiological care and cure, which is a Wholistic and Holistic intervention. I use the term “Wholistic” to refer to a person’s sense of being a whole human being, experiencing congruency and continuity as an integration of all dimensions of being. I use the “Holistic” to refer to a person’s sense of mystery, power of the divine and religious experience. This means that, the human being is created as an interdependent, interrelated and interacting system. The human being is a person created by interaction with family, community and society. Each system is connected to the other, whether healthy or when

⁷Phyllis Tyson and Robert L. Tyson, *Psychoanalytic Theories of Development*, (New Haven and London: Yale University Press), 1990, xi.

disabled. In the final analysis, able-bodied persons and disabled persons are created in the image and likeness of God. All are called to live in relationship to God and to one another. This means that, all persons with disability should be included in all aspects of life within the families of origin, community, and nation.

Complex Living Human Document: Multiple Faces of Disability

The major foci of interest and study in the psychoanalytic developmental psychology are: development, psychosexuality, object relations, behavior, affects, cognition, the ego and superego, and gender.⁸ The implications to this chapter are psychological, optimal and pathological development, and disability is defined in these nine categories. The adaptive functioning of a person as discussed in this chapter is interdependence. This means that a person is able to cope with stresses of life in relation to other persons in the family, community and kinship. I have discussed the optimal personhood in Kenya and Africa as the Relational Self-in-Community (Ikenye 2002, pp 75-84).⁹ The skills in adaptive functioning include communication, self-care, homing (daily) living, social and interpersonal skills, use of community resources, functional academic skills, work, leisure, health and safety. Mental or psychological disability must focus on impairment in the adaptive functioning; resulting in life long care and challenges.

The International Classification of Diseases and American Diagnostic and Statistical Manual of mental disorders have a nosology or classification of psychopathology.¹⁰ In Axis I for clinical syndromes, mental disabilities include mental retardation, learning disorders,

⁸Ibi., 3.

⁹Ndung'u J.B. Ikenye, *African Christian Counseling: Method, Theory and Practice*. 2002, 75-84.

¹⁰American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition. Washington, DC, 1994., pp.37-77, 350-359.

developmental coordination disorders and communicative disorders. The pervasive developmental disabilities that result in sub-average intellectual functioning include: autistic, Rett's, disintegrative, Asperger's and developmental disorders.

Autistic mental disability is characterized by impaired development in social interaction and communication, restricted repertoire of activity and interests, and impairment in multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures and gestures to regulate social interaction.

Rett's Disorder is characterized by multiple developmental deficits but the regressive factor of getting worse and worse is more apparent, loss of social engagement, poorly coordinated gait or trunk movements, and severe impairment in expressive and receptive language development. The disintegrative disability is characterized by a marked loss and regression in multiple areas of functioning such as verbal and nonverbal communication (expressive and receptive), social relationships, play, adaptive behavior. A disabled person with this disorder will be getting worse in social interaction, especially with peers, and will have delays in or lack of social or emotional reciprocity, and inability to sustain or initiate a conversation; such a person will have restricted, repetitive and stereotyped patterns of behavior, interests and activities, and mannerisms.

Asperger's Disorder is characterized by a severe and sustained impairment in social interaction and development of restricted, repetitive patterns of behavior, interests and activities. There is marked preoccupation with one or more with abnormal intensity, inflexible adherence such as hand or finger flapping or twisting mannerisms. This disabled person has impairment in the use of multiple nonverbal behaviors such as eye to eye gaze, facial expression, body postures and gestures to regulate social interaction. These impairments cause disturbances in social and occupational functioning. This person is not impaired in language or cognitive development. In this category, there are severe and pervasive disabilities of delirium, dementia, amnestic, and cognitive disorders.

Pervasive Developmental Disorder is a disability characterized by severe and pervasive impairment in the development of social interaction, verbal and nonverbal communication skills. There are also impairments in stereotyped behaviors, interest and activities. The other category in this area of mental disability is severe disorders related to schizophrenia and psychosis. There are also severe mood disorders that cause disability such as chronic major depression, bipolar, anxiety, and somatoform, factitious and dissociative disorders. Of importance in our discussion is the severity which results in permanent disability.

In Axis II, there are severe personality disorders that become pervasive to qualify for disability. Psychopathic personality will have problems of attachment and psychological organization. This person will be disabled due to the fact that, he or she has secondary autistic disorders. A severe schizoid personality will have a disability as a disorder of attachment throughout life. The loneliness and emptiness will make that person disabled, although this person will not be in danger of psychotic fragmentation. We have also to be aware that, psychosis is a disability in its worst form. These persons need lifelong care.

In Axis III, there are severe general medical conditions such as nervous, circulatory, respiratory, digestive and urinary conditions that qualify for disability. Mental disability disorders are categorized as pervasive, severe, moderate and mild, profound, or disturbed. DSM-IV used above does not have a direct reference to disability. My experience in individual, couple and family counseling and as a priest has shown that, disabled persons exist in all these areas and levels of this nosology. In the psychoanalytic tradition from which this nosology emanates, "we are able to confront the complexity of the human condition in general and the idiosyncrasy of each individual human being in particular."¹¹ This psychoanalytic tradition presents

¹¹Nancy McWilliams, *Psychoanalytic Diagnosis: Understanding Personality Structure in the Clinical Process*, (New York: The Guilford Press, 1994), viii.

major treatment modalities as individual, marriage and family, group and pharmacological therapy.¹² There is no specified treatment for disability. Nor does the long life care for the disabled implied or mentioned directly. My deduction from the psychoanalytic tradition is that, counseling will support a disabled person to make disability ego-syntonic, as a part of one's own being. In counseling, a disabled person, his or her family and community will work on the reality, regulation, relationships, thought processes, autonomous functioning and meanings of beauty in the midst of disability.

Disability, Care Systems, and Practical Theology

In disability care, there is a pentatonic focus. This biopsychosocial model is inclusive of biological, psychological and social care. There is an imbalance in this model for care of disabled persons. Disabled persons are spiritual beings and they live in contexts and environments. This chapter, I hope will raise the level of awareness to the other needs of disabled persons, and thereby correct the imbalances that exist in understanding their needs, diagnosis of their problems, and in the conceptualization of the multiple frameworks of care, for and with the disabled. The spirit of theoretical and Wholistic care is emphasized in the care systems.¹³ This Wholistic care goes beyond the counseling office and hospital bed to the community and society. This Holistic care is not only an interest of psychology but also an interest of practical theology. Practical theology on one hand seeks to understand how the context, structures and dynamics of being affect personal and shared life.¹⁴ For example, disabled persons need specialized pastoral care and counseling from the church and its ministers. The church physical structures need to cater for the needs of the disabled. On the other hand, practical

¹²Ibid.

¹³Glen O. Gabbard, *Psychodynamic Psychiatry in Clinical Practice*, (Washington, DC: American Psychiatric Press, 1994), xvi.

¹⁴James N. Poling and Donald E. Miller, *Foundations for a Practical Theology of Ministry*, (Nashville: Abingdon Press, 1985), 11.

theology is reflection arising out of living experiences (of persons of faith and their contexts) of communities of faith, resulting in faith informed interpretations that serve to guide ongoing life and actions of persons and their communities. Persons with permanent disability need not be made prayer items for miraculous healing. Rather, they need to be accepted as they are and integrated into the community of saints, as fellow saints. In this line of thought, the psychological perspective of pastoral and counseling care needs to address itself to the personal and communal contexts, structures and dynamics of being and of relationships that affect disabled persons. As we increase awareness and sensitivity, of the experiences and needs of the disabled persons, our shared future will be bright, as we make informed interpretations that guide our life and actions.

Noteably, practical theology is critical and constructive.¹⁵ The critical part helps us to do self-criticism of creation of awareness and knowledge of biases, assumptions and self interest that close the disabled persons out from intimate relationships in the community of faith. The constructive part helps us to affirm meaning and value of the disabled persons, as to who they are to us as a community and family system. This constructive part also helps us to understand and undertake our priorities, obligations, and responsibilities to eradicate misconceptions, stigmatization and negative attitudes toward disabled persons.

In the final analysis, the multiple dimensions of humanness in a disabled and able person attend to physical, mental, relational, communal and societal and environmental systems, with the underlying Ultimate Reality of God as the Supreme Being. Wholistic understanding will affect awareness of disabled peoples' needs (as they are, acceptance) and interventions (where they would want to be), and where community involvement (would like to be) as a holding and containing environment. The pastor's communication offers encouragement to the disabled individuals, taking into account the self-affirming and optimistic persons, falsely affirming

¹⁵Ibid., 62.

persons with problems of hastiness, ambivalent persons running with high anxiety, and depressed and sad persons. To minister to these people effectively and efficiently, the pastor must meet disabled persons at their points of need. As I discuss the next section on human development and themes in the psychoanalytic tradition, let this be a tool of deepening relationships with disabled persons.

Historical Perspective in Psychoanalytic Theories of Human Development

Psychological Development

The father of the psychoanalytic movement Sigmund Freud explained two core images of human development.¹⁶ The first image is that of development, from one stage to another throughout the life cycle. The second is that of conflict, from within oneself and from external interactions with others. The developmental perspective in all schools of psychology allows us to understand that, a disabled person may be at any of the stages of the human life cycle. Freud's developmental stages include the oral and anal stages of infancy (0-3 years), phallic stage of early childhood (3-6 years), latency (6-12 years), adolescence (12-18 years) and adulthood.¹⁷ Erik H. Erikson has an eight stages theory of human development: Trust vs. Distrust (infancy); Autonomy vs. Shame and Doubt (Early Childhood); Initiative vs. Guilt (Play Age); Industry vs. Inferiority (School Age); Identity vs. Role Confusion (Adolescence); Intimacy vs. Isolation (Young Adulthood); Generativity vs. Stagnation (Adulthood); and Ego integrity vs. Despair (Mature Adulthood).¹⁸ Daniel J. Levinson developed a theory of adult development showing age-linked phases

¹⁶Burness E. More and Bernard D. Fine, Eds. *Psychoanalytic Terms and Concepts*, (New Haven and London: The American Psychoanalytic Association and Yale University Press, 1990), 44-45, 55-56.

¹⁷Ibid. 56.

¹⁸Erik H. Erikson, *Childhood and Society*, (New York: W. W. Norton & Company, 1963), 247-274.

of adults, inclusive of their system of crisis, emotional states and attitudes, ambitions and dreams, success and failures, and shapes of behavior.¹⁹ Levinson's stages for adults are: Early Adulthood (17-22); Mid-Life (40-45); Age Fifty (50-55); and Beyond.²⁰ Theories of human development from the Freudian School are male-oriented. Carol Gilligan developed a women's theory of psychological development, emphasizing their relational being which informs their motives, moral commitment, self-esteem, maturity and self-actualization.²¹ These theories of human development emphasize the fact that human beings develop through stages. The stages are left behind but we carry the experiences psychologically as a process of being. Human development occurs in a social context, which contributes to strengths (positive and enhancing) and weaknesses (negative and crises creation). Disabled persons go through the same stages of development as non-disabled people. As shown above in my discussion of the multiple meanings and levels of mental disability, stages of development of a disabled person affect and are affected in mental disability.

Psychological developmental theories focus on the intrapsychic: contents, structure, origin, nature and processes of the mind. In this sense, the mind is understood in its relationship to functioning in the expression of feelings, behaviors, perceptions, language, thought systems and interpersonal interactions. The sum total of all parts is the personality. These developmental theories also explain the course and cycle of development, as changes and phases over a time line. These developmental changes and transitions from stage to stage have identifiable sequences, concurrencies, continuities and discontinuities, with principles for change.

¹⁹Daniel J. Levinson and Others, *The seasons of a Man's Life*, (New York: Alfred A. Knopf, 1978), 71-340.

²⁰Ibid.

²¹Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development*, (Cambridge, Massachusetts: Harvard University Press, 1982), 24 -174.

Models of Human Nature

The developmental paradigm in the psychology of persons suggests that, if occurrences or changes do not take place, then the cause of mental disability is known. It is here that the theory of nature and nurture comes into play in the psychological perspectives.²² There are four models of human nature.²³ The mechanistic model that sees a person as composed of interlocking parts, organized to a working whole. When we speak of a mentally disabled person, we must be particular as to what part or kind of mental disability.

The organic model sees a person a whole living system with inherent goals and properties. The whole is constantly changing, self-controlling, self-regulating and self-initiating. In this model, we are challenged to see a disabled person as a whole person with goals and properties which may be or not affected by the disability. The contextual model sees a person in a socio-political and socio-economic context. In this model, we are challenged to not only see a disabled person as a person with social and political rights and gifts. We are also challenged to see disabled persons as persons who can participate in social, political, and economic systems. Disabled persons have goals in their lives. Patronizing mentalities in the family and community will not help in the empowerment of disabled persons to meet their goals for life. When a disabled person cannot participate in these areas, we are challenged to understand their losses. The context gives meaning, direction, purpose and variation to the behavior of a person. We are also challenged to create contexts and advocate for contexts that will hold and contain the disabled persons.

The capitalistic model, in Charles Darwin's view focuses on "the survival of the fittest." Persons compete as they struggle for success and self actualization. With colonization, we imported fierce competition in Westernization. One of the issues that comes with disabled persons is their capacity to compete in a competition

²²Patricia H. Miller, *Theories of Developmental Psychology*, (New York: W.H. Freeman and Company, 1983, 1989, and 1993), 22-25.

²³*Ibid.* 17-20.

oriented society. On one hand, the challenge given by this model is to understand and measure the abilities of a disabled person to compete. Depending of the level of disability, disabled persons can compete with fellow disabled and able Persons. On the other hand, if the disabled person cannot compete, we have to join that person at their points of need and compete for him or her. Able persons can be the empowering voice for the disabled person. Able persons can be the agents of competition with the disabled persons. Able-bodied persons can join disabled persons as transformers and facilitators of their empowerment.

The Use of Defenses

Mental disability is closely related to the physical nature of a disabled person. The environment of personal experience, as to whether it is supportive or inhibiting, has an impact on the mental state of a person. To fit into, or react to an environment, a disabled person has to learn and condition herself or himself to make a psychological order for enforcement or use aggression. Sigmund Freud researched extensively of the theory of conflict and use of aggression. Aggression manifests itself either physically or verbally. It may be in the form of an overt attack or in covert, indirect, and disguised form. For example, one may use jokes as a passive way to show resentment toward a disabled person. A family living with a disabled person may use aggression to hurt and exclude, or exploit. Aggression can be used to show anger toward a person who is disabled. The disabled person may use aggression as a hostile or non-hostile expression of feeling. A disabled person may use aggression as a reaction to being abused, neglected or excluded. A disabled person may use aggression for self-assertion and self-preservation, to demand an audience or action.

Conflict as a psychological experience may refer to struggle among incompatible forces or structures. For Freud, conflict as occurring between unconscious wishes and the conscious dictates of communal morality. This conflict is manifested in symptoms, actions, and thought. Defenses are mobilized to handle and resolve

anxiety produced in the conflict between the ego (reality) and prohibitions (internal and external). Freud's daughter, Anna Freud (1936, 1946)²⁴ continued his work on mechanisms of defenses.²⁵ Defenses are systems of "protecting the ego (reality) against instinctual demands from the id (drives)," said Freud in 1926 and 1959. Disabled persons or those living and working with them may use one or both forms of defenses to run away from the reality of disability or cope with the person with the disability. The first forms of defenses are called the primitive or neurotic defenses.

These include repression (expelling all the unacceptable), displacement (redirecting feelings from one source toward another), reaction formation (adopting a trait that is diametrically opposed), isolation of affect (avoiding an affect, for example by intellectualization or rationalization), undoing (magical thinking or symbolic action to reverse or cancel), somatization (transferring of painful feelings to body parts) and conversion (symbolic representation of an intrapsychic conflict into physical terms). The mature defenses of dealing with disability and the disabled are suppression (conscious banishing of unacceptable thoughts and feelings from the mind), altruism (subordination of ones own needs and interests to those of another) and humor (being playful about the situation.) Those living or working with a disabled person, can psychologically use the neurotic defenses and not deal with the needs of a disabled person. On the same side, a disabled person can use the neurotic defenses and not face the reality of the disability.

Creation of a Living Environment

For our purposes in this study, a disabled person will reinforce and appreciate acceptance and support, or use aggression to show frustration, or be passive if the disability is severe. On the other hand, those living or working with the disabled will decide whether

²⁴Anna Freud, *The Ego and The Mechanisms of Defense*, (New York: International University Press, Inc., 1966), 42-53.

²⁵Gabbard, *Psychodynamic Psychiatry*, 30-42.

to be accepting, supportive and nurturing, or use aggression to oppress and abuse the disabled person. One of the concerns here is that of acculturation to oppression and abuse of the disabled.²⁶ In this process, the disabled is forced to re-learn and re-socialize, to fit into abusive and oppressive systems and relationships. The trauma of this learning and socializing create a new set of problems. Cognitive adaptation between the person and the environment, as an intelligent choice, is an appropriate behavior in response to the demands of the environment. Adaptation involves two processes, namely, assimilation and accommodation.²⁷ In assimilation, a person fits and incorporates new reality into the current cognitive organization. A person may use any of the four types of assimilation: functional reproduction (again and again); stimuli of various objects (by use of stimulation); recognition of various objects; and mutual coordination.²⁸ Disabled persons or the contexts of their being can assimilate the environments, for their good or for their suffering and disaster. In accommodation, a disabled person adjusts the cognitive organization map in response to demands from the reality of disability.

Adjustments are also done when particular objects or events cannot be interpreted. All forms of adaptation and assimilation are geared toward achieving equilibrium. Whether a disabled person has grown with the disability or the disability has come as one goes through the stages of development, equilibrium is necessary. On the other hand, disability causes disequilibrium on the disabled and the family and community. A disabled person, family or community has to come to a point of optimal living with the disability. Disabled person and disability are received with acceptance and hope, and thereby adapted into life's way and journey. This point of equilibrium comes by balanced coordination of all dimensions and facets and leads,

²⁶Ndung'u J.B. Ikenye, *Decolonization of the Kenyan Soul*, (Nairobi, 2002), 15.

²⁷*Ibid.*, 14-21.

²⁸ Miller, *Theories of Developmental Psychology*, 68.

positively speaking, to a balanced way of functioning. The danger of equilibrium, negatively speaking comes when oppression, marginalization and abuse of a disabled person are regularized and are part of the equilibrium. Miller articulates three form of equilibrium: moment-to-moment; moving forward to a level or stage, and entire course. All these equilibrations must be understood cognitively to help in the adjustment and incorporation of a disabled person and vice versa in relation to community and family.

Disability and Psychoanalytic Themes of Human Functioning

The Innate Human Capabilities

The first theme in psychology that affects our view of disabled persons is their innate capabilities.²⁹ The assertion here is that, persons live under optimal environments to develop particular capabilities. All persons bring their hereditary biological and physiological components to the environment with which they interact to attain particular mental skills and temperament. Due to problems in the environment, mentally disabled persons will be seen not to have attained, or may have attained lower levels of these skills and temperament. The disabled person will lack in optimal activity levels (for example, IQ), rhythm, adaptability, and reactionary threshold when faced by the ego (reality) and superego (right/wrong). Disabled persons depending on the severity of the disability may have problems of distraction, persistence, attention, intellectual potential and interaction, and inability to receive, process, and express language or feelings and emotions. Disabled persons may be unable or have difficulties in achieving cognitive and relational homeostasis. Disabled persons may also have problems of self-integration; hence have difficulties of having skills for adaptive coping. In sum total, depending on the psychological severity of damage to mental structures and contents, disabled persons may not be able to

²⁹Tyson and Tyson, *Psychoanalytic Theories*, 22-25.

initiate, maintain, and terminate interactions with others. Disabled persons may not be able to self-regulate, engage human resiliency, or distinguish between what is pleasurable and not pleasurable. What this innate view brings to this discussion is the necessity of knowing the awareness level of the disabled person, in terms of their capabilities in cognition, perception, motor skills, and relational adaptiveness. These pre-conditions affect their ability to initiate, maintain, and terminate thought and relational processes. Their capacities will affect the level of attachment, and capacity to interact and shape their environment.

Capacity to Experience and Express

Experience as a theme of psychology involves human participation or encounter with reality. Human beings experience by participation as a near-experience or by reflection. In experience, a human being gains knowledge. For our purpose, the experience of a disabled person involves that person's participation. A disabled person can sense data with immediacy in the occurrence. Second, a disabled person can reflect and gain knowledge. Depending of the severity of disability and the innate capacities, the disabled person will or not be able to interact, adapt, or shape the environment. This also means that, there are limits to the disabled person's quality of experience. The issue of limitation in experience limits the quality of interaction with other persons. If the mental disability has not rendered a disabled person without this capability, mutual interaction will take place between the disabled person and the world around him or her. The disabled person has an implicit understanding of being, of doing, and of becoming within the limits of capacity for freedom and responsibility. Disabled persons have the capacity to predict and control, and thus build their own experience. They are able to experience and express in new ways as a result of encounters and interactions, therefore they have their own expectations in particular given situations.

Structure and Contents of the Mind

The other psychological theme is that of psychic structure and contents of the mind. The psychic structure comprises of the id (driving energy), ego (reality) and the superego (sense of right and wrong, commonly called conscience). The contents of the mind are the conscious (known), pre-conscious (partly known and partly unknown) and unconscious (completely unknown). These contents and structure of the psyche are what organize the structure of personality. Any deficits of a personality in turn affect the capacity to function or organize in daily life experiences and interaction with the world. Any deficits, defects and deficiencies affect developmental processes of differentiation, attachment, organization, transformation, negotiation and systems of shaping experience and networking with others. Those living and working with disabled persons need to assess these issues, hence be able to respond appropriately. By understanding the structural, organizational, personality and functional deficits, people will be more empathic in their responses to the disabled.

Sexual Development

Another theme in psychology is sexual development. Sigmund Freud is notable for bringing a hidden and prohibited subject to the public domain. Between 1905 and 1915, Freud had developed a theory of sexuality, summarized by Fenichel.³⁰ Sexual disability is rarely or spoken of as disability. Disabled persons are mistakenly seen as asexual. Sexuality, sexual development and sexual disability should be discussed, as it affects many able and disabled persons. In the African continent, the birth of children is understood to be a blessing, and lack of children, a curse. Lack of sexual drive development, in terms of the forces (libido), or urges and stimulation, at any stage in life or throughout the life cycle need to be discussed and normalized. Sexual drive motivates psychic development. Deficits or disturbances of sexual development

³⁰Otto Fenichel, *The Psychoanalytic Theory of Neurosis*, (New York: W.W. Norton and Company, 1945), 33-113.

disturb personality development. Libido problems bring about problems of aggression as well as motivational processes in individuals. Like other persons, disabled persons are sexual beings. Disabled persons have need for sexual gratification, if the erogenous zones are not part of the disability. The sexual rights of the disabled persons must be protected, and not denied, disregarded or abused. Society and governments must protect the sexual rights of the disabled, in fact not only by taboos but by law.

Relationships and Relational Systems

Another theme in psychology is object relations as developed by Sigmund Freud between 1895, 1923, 1924, and 1931. Objects are persons. Objects are also components of psychological internalization of interactions with other people. The emphasis here is need of relating to other persons to meet particular needs. Secondly, persons seek out persons to relate to and interact with, for socialization. As Freud developed the “Oedipus Complex” theory, he observed that objects are the vehicle to instinctual gratification. Freud noted that, there are two kinds of objects. The first kind of object is the people that a person interacts with at the conscious and manifest level. The second kind of objects, are internalizations of those interactions and experiences into the psyche, thus becoming mental representations at the unconscious and latent level. What this means is that, interactions with a disabled person are psychologically gratifying, regulating their existential anxiety and maintaining of their homeostatic equilibrium.

On the other hand, poor interactions, or lack of interactions with a disabled person will cause psychological trauma. More specifically, mild and moderately disabled persons will seek out persons who are gratifying at both levels. Non-gratifying and abusive objects (persons) will be avoided at any cost by disabled persons. Another component that I have found with disabled persons is that the object relationship is a part of their disability. A disabled person may have relational disability which is ego-syntonic or ego-friendly. Such a person should be respected as such, and be

allowed to be into relationships. There are disabled persons whose disability makes relationships ego-dystonic or ego-alien (foreign). Their mental apparatus is not ready for relationships. Such persons should not be forced into relationships, hence the need for protection from relational predators.

Affects, Feelings and Emotions

Another theme in psychology is the affects. Affects are central to personal psychological world, to the interpersonal world, and to interacting with the environment. As mental structures, affects have motivational, somatic (physical), expressive, communicative, and emotional or feeling components. The affects are associated to the cognitive components of the mental structure. Feelings and emotions are the experiential or behavioral aspects of affects. Affects are immediate and are of urgent quality. For a person who is affects disabled, there is a deficit in the psychological and relational world. In interactions, disabled persons with affect deficit and deficiency experience quantitative, massive and intense affects, mainly if their bodily processes are also linked to the disability. But if the disability does not include deficits in affects, like all persons emotions and feelings are essential to their being human.

From 1962 to 1981, S. S. Tomkins studied positive and negative affects, and in relation to facial expressions.³¹ He came up with a list of nine categories: interest-excitement, enjoyment-joy, distress-anguish, fear-terror, anger-rage, shame-humiliation, contempt and disgust. From this list, we can see that, affects are intrapsychic signals of positive or negative emotional expression.. Lack of affect experience or denial of effect expression may lead to disorganization of ego-functioning, internalization of experience, and identification with objects. Disabled persons should be allowed to experience affects so that they may facilitate organizing reality and regulate functions, and adjust their lives.

³¹S.S. Tomkins, (1962). *The Positive Affects* Volume 1 and *The Negative affects*, (1963), Volume 2, (New York: Springer).

Cognitive Ability and Use of Thoughts

Another theme in psychology is cognition. Cognition encompasses perception, imaging, concept formation, thinking, judgment, and imagination.³² All these aspects of a person's cognition give meaning, richness, quality and nuances to the inner world. Any form of cognitive disability affects a person's quality of life. Cognition affects interaction development, capacity to communicate, symbolize, learn and reason. Sigmund Freud in 1900 designated two forms of thinking.³³ Primary thinking was characterized by concretism, condensation, displacement, and visual imagery. These characteristics are expressed in the unconscious and inner world of a person. This thinking is expressed through unconscious fantasy, fantasy play, day and night dreams, magical thinking, and slips of the tongue, jokes, and artistic and creative activity. A person with a disabled cognition misses a lot in life, but for a person who is not cognitive disabled, a lot is happening in their inner world. All these primary processes continue as functions of the mind. The second kind of thinking is called secondary process. Secondary processing is a conscious or unconscious process characterized by reality, rationality, order and logic. A disabled person, engaged in secondary processes, though seated on a wheel chair, blind, deaf, or walking on crutches has a lot going on in their lives.

Use of Reality, Right and Wrong

Another psychological theme is that of the ego (objective and subjective reality) and superego (conscience). The ego mediates between individual and external reality. Ego functions include: perception, object and reality relationship, defensive, regulative, synthetic, integrating, autonomous and executive function. The superego is the internal representative of the standards of behavior and moral demands of society and its institutions. Ego disability is incapacity or impairment in one or more of the ego functions. Ego disability and defects may be constitutional, maturational, experiential

³²Moore and Fine, Eds. *Psychoanalytic Terms and Concepts*, 42.

³³Tyson and Tyson, *Psychoanalytic Theories*, 164.

and developmental. Superego defect and disability is incapacity or impairment in systems of ideals and values, prohibitions and commands (the conscience), observing and evaluating self, comparing, and either reproach and punishment. Superego disability means that, one does not have the inner voice as an authority and judge. Without deficits, impairment, defects and disability a disabled person would be experiencing the same ego and superego functions as the non-disabled person. Disabled persons have moral standards, voices of conscience, values, ideals and reality, all of which must be respected. The moral standards applied legally, socially and spiritually to non disabled persons must also be applied to disabled persons.

Use of Gender Identity

Another psychological theme needing our attention is gender. By creation, nature and nurture we are gendered. Meaning that, gender identity is a psychological configuration. Gender identity combines personal identity, biological sex, interpersonal experiences, intrapsychic consequences of identification, and social-cultural influences. An individual's sense of gender identity is the overall sense of femininity or masculinity. Gender-role identity is a gender and role characterized by assumption of what is consciously or unconsciously brought from interactions with others. It will suffice to mention that, disabled persons are gendered like every other person. A disabled person's gender identity and gender-role must be respected and protected. Gender identity disability is impairment of personal identity, psychosocial components and biological sexual orientation. These sexual and identity impairments may include denial, shame or guilt.

Another issue we need to address is sexism, that is, discrimination against, domination and exploitation of disabled women by men. We have seen the sexism in a different and opposite light, where disabled women are raped for self-cleansing of males living with HIV and AIDS. The underlying misogyny (hatred of women) and gynophobia (fear of women) in societies are extended to disabled women. Sex education for the disabled is also an interest of psychology in that it is designed to deal with and minimize confusion

and anxiety. Such education will provide direction and empowerment for the disabled persons as they make informed sexual decisions. Sex education will educate disabled persons about sexual deviance and disorders³⁴ such as exhibitionism, fetishism, frotteurism, pedophilia, sexual masochism, sexual sadism, transvestic fetishism, voyeurism and paraphilia. These sexual perversions are based on mental fantasies.

Use of Culture

Another psychological theme that affects living and working with disabled persons is culture. Culture is an organized body of rules concerning the ways in which individuals in a population should communicate with one another, think about themselves and their environments, and behave toward one another and toward objects in their environment.³⁵ Culture is the “life ways of the people,” and understood through the core value and the value system. Each person is enculturated into the life ways, and that learning is internalized to become part of the person. The rules of cultural functioning limit the patterns of communication, thinking, relating, belief, value and social behavior. Culture also defines the boundaries of inclusion and exclusion. I was reminded by one student as I was writing this paper that some of the cultures associate disability with a bad omen, or a curse to the person and or the family. The challenge here is whether

³⁴Fetishism is sexual urges and arousal by use of non living fetishes or objects. Exhibitionism is sexual arousal by exposure of genitals to strangers. Frotteurism is sexual arousal involving rubbing and touching a nonconsenting person. Pedophilia is sexual arousal and activity using a child. Sexual masochism is sexual arousal by use being humiliated, bound, beaten or made to suffer. Sexual sadism is sexual arousal by making another physically suffer or by humiliating them. Voyeurism is sexual arousal by involving an unsuspecting naked person, or contact with a person. Paraphilia is sexual arousal involving telephone conversations, corpses, parts of a body, or animals. All these disorders involve sexual fantasies.

³⁵Robert A. LeVine, *Culture, Behavior and Personality*, (New York: Aldine Publishing Company, 1982), 4.

the culture accepts or rejects the disabled person. Of the forty one ethnic communities in Kenya, there are ethnic, cultural and religious heritages that are prized, protected, nourished and cherished as guides to life ways. The challenge here from cultural psychology is that fact that, disabled persons are excluded from all these heritages. All ethnic groups must be challenged and encouraged to include the disabled persons in their cultural training and functioning. Disabled persons must be supported by culture to find a niche in their communities. Disabled persons must be empowered to become interdependent, independent, and self-reliant.

Personality and Traits

The last psychological theme that I would like to raise is personality. Personality is the outcome of a lifelong process of interaction between organism (nature-biological hereditary part of self) and environment (systems of nurture that are internalized- psychological part of self). These complex psychological processes that are internally placed determine consistencies unique to the individual. Personality is a combination of attributes, values, behaviors and temperaments, and traits, unique to a person. From the days of Sigmund Freud, different theories have been developed to show the formation of personalities and unique traits of each personality type.

For example, the psychogenetic view of personality acknowledges that, an individual's past has influenced the current functioning.³⁶ Theodore Millon sees personality development in terms of processes between environmental and organismic forces that influence the life of the individual with mutuality and circularity, in an orderly and sequential continuity.³⁷ Millon articulates eight basic personality types, which are submissive, gregarious, narcissistic, aggressive, conforming, negativistic, asocial, and avoidant.³⁸ These

³⁶Tyson and Tyson, *Psychoanalytic Theories*, 7.

³⁷Theodore Millon, *Disorders of Personality*, (New York: John Wiley and Sons, , inc., 1981), 67.

³⁸*Ibid.*, 91-91.

theories of personality suggest that disabled persons should be particularized as individuals, each with unique personalities. There is tendency to lump disabled persons together and over-simplify their complexity. I suggest that, each person living or working with a disabled person should take time to know their unique character, traits, strengths and weaknesses, and their diverse and unique ways of thinking, coping, behaving and relating.

Psychological Disability as Loss of Function

The three categories of definition; impairment, disability and handicap have one thing in common, that is, loss of function and or limitation in functioning. Loss may come by accident, illness, genetic abnormality, or by normal aging. Any loss is an accompanied crisis. In teaching a course on bereavement, it has become obvious to me that, all losses require time to mourn and heal. In grief work, as one goes through the stages of recovery there is need to adjust, adapt and accept to live with loss of function. If a person has attached more significance to the part or function, the bigger the reaction to the loss, and more time and grief work will be needed. If the loss is slight, partial, or incapacitating, then extensiveness will determine the psychological disability and pain. The other factor is that of earlier and previous losses which complicate bereavement and recovery. In cases where a disabled person has unresolved grief or complicated grief, this will increase anxiety and interfere with adaptation, healing and acceptance of the loss reality.

The level of personal psychological maturity (self-integration or self-differentiation) affects the level of psychological disability. If a person has a weak ego or ego-deficits, the self is loosely or tenuously integrated and enmeshed in attachments. The diffusions are the result of lack maturity and complicate adaptation and coping skills. Any or more of the psychological themes may complicate losses and result in severe disability. As disabled persons or their families are supported to do the grief work, the processes of shock, denial, bargaining, anger, depression, ambivalence, integration and acceptance will need focus.

Disability Change and Care: Borrowing a Leaf from Pastoral Care and Counseling Psychology

Love is one of the most unifying powers in life. Paul Tillich defines love as, “the moving power of life that brings the unity of the separated.”³⁹ This love is the therapeutic force and requires the elements of valuing the other, friendship, and self-giving. Love was named as “positive attitude” by Carl R. Rogers⁴⁰. The emphasis of open-mindedness, hospitality and genuine welcome go a long way in accepting disabled persons. As the disabled person faces suffering, pain, and anxiety due to the losses, hope is incarnated in caring relationships. In these relationships we become coaches and midwives to them as they give birth to the new self. Disabled persons must be accepted as persons of integrity and worth. Disabled persons do not need sympathy, rather each disabled persons seeks empowerment, acceptance and relationships. Unless disabled persons are severely disabled, their sense of self-direction must be respected. To work and live with a disabled person requires both empathy (feeling with and entering their feeling frame of reference with compassion) and interpathy (thinking and feeling with, relating with). In empathic presence and entry, one has to view the disabled person from within and entering their feeling frame of reference. In interpathic presence and entry, you seek to enter into the whole world of a disabled person with the intention of listening and learning of their experience.

Conclusion

In this chapter, I have discussed the psychological effects and psychological dynamics in the life of a disabled person. I have shown through psychological themes that, a disabled person is multidimensional, and should be treated as such in all aspects. I have also shown the psychological meaning of disability as loss. I have

³⁹Paul Tillich, *Love, Power and Justice*, (London: Oxford University Press, 1954), 25.

⁴⁰Carl R. Rogers, *Client-Centered Therapy*, (Atlanta and Boston: Houghton Mifflin Company, 1951), 34.

shown that, the disabled person is a whole person, complex like all other human documents. To accept and appreciate disabled persons, individuals, families and society at large have to enter into their frame of reference.

Disability, Society, and Theology: Voices from Africa

CHAPTER SEVENTEEN

Psychosocial Disability: Attitudes and Barriers to Social Integration in Church and Society

Janet Amegatcher

What is Psychosocial Disability?

Psychosocial disability is a form of ‘mental illness’ that occurs in an individual and affects the person’s psychological pattern. It is thought to cause distress or disability that is not expected in ‘normal’ development.

There is no known single cause of psychosocial disability. However, combinations of medical and social models have been identified as some of the causes. They include genes, environmental events surrounding pregnancy and birth or traumatic brain injury. Other causes include viral infections, substance misuse, emotional processes, personality, temperament and coping style, and general physical health. There are two types of disability, medical and social.

Medical Type of Disability

According to Wikipedia, free encyclopaedia [1], the medical model of disability is a model by which the disability is the result of a physical condition, is part of that individual’s own body, reduces the individual’s quality of life, and causes clear disadvantages to the individual.

Therefore, to cure or manage such a disability, you have to identify the illness or disability, understand it and learn how to control it. A just society invests resources in health care and related services so as to improve the health of its people, including the disabled. Disabled persons should be allowed a more “normal” life.

The medical profession’s responsibility and potential in this area is central. The medical model of disability is often cited by disability rights groups when evaluating the costs and benefits of various treatments. Quite often, a medical model of disability is used to justify large investment in complex procedures, technologies and research. One of the solutions is adaptation of the disabled person’s environment.

Some disability rights groups, as noted in the Wikipedia, see the medical model of disability as a civil rights issue. They are critical of medical initiatives that use it in their portrayal of disabled people, because it promotes a negative, disempowered image of people with disabilities, rather than casting disability as a political, social and environmental problem.

Social Type of Disability

Wikipedia [2] also states that the social model of disability proposes that barriers, prejudice and exclusion by society are the ultimate factors defining who is disabled and who is not in a particular society. The model recognises that some people have physical, intellectual or psychological differences from the known statistical mean, which are actually impairments. However, they do not lead to disability unless society fails to accommodate and include them in the way it would those who are ‘normal.’

The phrase ‘differently abled’ is sometimes used to convey an aspect of the social model of disability. Laura, Arntson and Christine Knudsen[3] argue that the term ‘psychosocial’ has been developed to include the complex nature of child development. It builds on close interplay of the psychological and social aspects of growth. A child’s psychological development includes the capacity to perceive, analyse, learn and experience emotion. Social development includes the ability

to form attachments to caregivers and peers, maintain social relationships and learn the social codes of behaviour of one's own culture.

Therefore, there is a connection between a child's feelings, thoughts, perceptions and the development of the child as a social being within his or her social environment. Children's reactions to extreme events will vary according to individual characteristics and environmental factors. Psychosocial programming supports the child's cognitive, emotional and social development holistically. It also strengthens the child's social support systems. Thus, we put emphasis on strengthening social environments that nurture children's healthy psychosocial development at various levels, with the family, community and children themselves. At all levels, psychosocial programming must keep in mind the best interest of the child.

Understanding Depression

Depression is a form of psychosocial disability, is a mental state in which one is sad and feels he or she cannot enjoy anything, because the situation is so difficult and unpleasant. While we feel sad at different times, depression has enormous depth and staying power. Even the ancient Greeks noted how disabling it could be, and that it was more than a passing bout of sadness or dejection, or feeling down in the dumps .

This illness cannot be lifted at will or wished away. Persons with depression can not solve their problems by being assertive.

Depression could be described as 'a lake fed by many streams'. Its tributaries include traumatic or stressful life events such as the death of a loved one, psychological traits such as a pessimistic outlook, or a tendency towards isolation. According to the National Institute of Mental Health (NIMH), approximately one in ten adults suffer from some form of depression during a given year. Each depression episode usually affects a chain of people. It can fray bonds between you, your family and friends by spoiling intimacy, sapping emotional resources, and stealing the joy of shared pleasures.

Hopper et. al, argue that what the social model analysis calls for is social change. They argue that opportunities must be provided by the social environment. To ensure capability, social circumstances must offer opportunities for individual competency to be developed and exercised.

They further argue that social integration is a process, unfolding over time, through which individuals who have been psychiatrically disabled increasingly develop and exercise their capacities for connectedness and citizenship. By connectedness, they mean the construction and successful maintenance of reciprocal interpersonal relationships. These relationships should provide not only companionship and a good feeling but also access to resources. They include persons without psychiatric disabilities who are outside the mental health system as well as those with disabilities. [6]

Synthesis

From the above analysis, we can see that psychosocial disability relates to both the psychological and social aspects of a person. The term *psychological* refers to that which affects the mind, behaviour, attitude and conduct of a person. The *social* refers to that pertaining to life in an organised community.

Using the social model of approach, mental illness could be a disease but the stigma, stereotypes and negative attitudes cause a psychosocial disability by killing those affected legally by referring to them as persons with an unsound mind. This denies them their fundamental human rights and dignity.

Personal Experience

Some time ago, I developed psychosocial problems. I was sent to a psychiatrist in Ghana who prescribed certain oral drugs and injections. I refused to take both and instead sought a second opinion from my aunt who is a psychiatrist in London. After examining the drugs, she concluded that they were too strong. So, she gave me a substitute – milder capsules. I later returned to Ghana fully healed, after holidaying for about four months.

Four years later, my father died. This really took a toll on me. I again went to London for a holiday. While there, it was obvious that something was amiss – I was depressed. My aunt gave me three injections on three different occasions. After that my mouth started drooling with saliva. I suffered from a stiff neck and muscle pulls very frequently – even while asleep. I was very confused. My aunt decided to stop the injections and gave me some tablets to take when necessary. I then returned to Ghana.

I went to see another psychiatrist, who wanted to continue with the injections. So, once more, I sought my aunt's opinion. She told my husband that the drugs were destructive and that if they continued with the injections, they would destroy me.

So, I refused. Thereafter, my mind began to gradually clear. I started understanding when people talked to me. With time, I was able to go back to work.

If the other psychiatrist had continued with the monthly injections, I do not know what the result would have been. I believe that faith in the Almighty God played a great part. Although I could not pray or read the Bible very much, I knew that others were praying for me and God would answer their prayers.

I have a cousin who experienced psychosocial problems some years ago. He was put on monthly injections. Unfortunately, the injections have rather destroyed him. He has never been able to go back to work. He walks about laughing and talking to himself. Other times, he talks to people about non-existent things. His sisters are now sorry that they allowed him to be injected on a regular basis as prescribed by a psychiatrist.

Present Concerns and Challenges

Persons with psychosocial disability have many concerns and face many challenges as outlined below.

Primary Schooling

Some educators and parents think that putting students with psychosocial disabilities into regular classrooms may disrupt school activities

or require more time for teaching. They worry that their inclusion slows educational progress both for students with psychosocial disabilities and for their peers with no psychosocial disabilities.

Lack of Information

There is a dearth of information on mental health issues not only in Ghana but also other African countries. This has resulted in a lot of myths and uninformed claims about persons with psychosocial disability. Worse still, no one knows what to do in case of a problem.

Because of superstition, people associate mental problems with punishment for misdeeds. Persons with such disability are ignored or left to roam about. Others are sent to spiritualism churches or camps where they are chained and beaten on the pretext that evil spirits will leave them.

Some people take persons with psychosocial disability to [mental] institutions and abandon them there. After treatment, they find that they have no home or shelter to go to. This has led to overcrowding at the such institutions. Feeding has therefore become a very big problem. Sometimes, patients are fed only once a day, meaning they go hungry for the rest of the day. This forces them to go out to beg for food or pick leftovers.

Other myths or beliefs say that the mentally ill are dangerous, perhaps because of the way they are portrayed by the media. Another myth is that the mentally ill need to be hospitalised, drugged or injected. In fact, they benefit more from community based therapy. The fears that the media and cultural beliefs generate all combine to bring about the attitudes and create barriers for persons with psychosocial disability in both church and society.

Street People

As we approach golden jubilee independence celebrations this year, it is likely that persons with psychosocial disabilities will be 'kicked' from the streets and locked away. For example, those suffering from schizophrenia will be collected from the road side and dumped in

mental institutions without any supplies. This has been done before and we can predict that it will happen again.

Exclusion from Family Activities

Persons with psychosocial disability are excluded from family activities like meetings, funerals, decision making and any form of contributions. The same is the case for household activities such as cleaning in the household, cooking, washing, household maintenance and repairs. They are also excluded from national and community activities such as communal labour, payment of taxes, festivals, elections and decision making organs. Participation in these activities is a sign of the social integration of the individual.

Barriers to Social Integration

Lack of acceptance, poor personal relationships, inadequate income, disrespect and a muted political voice are some of the barriers to social integration. These result in social exclusion, as discussed below.

Lack of Funds

A major barrier to the social integration of persons with psychosocial disability is the lack of funds. Persons with this condition usually end up losing their jobs. Without being employed, they earn no money. Their families usually feel that it is expensive to take care of the person affected. Some will therefore abandon their relatives at a hospital or prayer camp because they see them as economic burdens. This means rejection and shame – hence is a barrier to social integration.

Stigmatisation

There is widespread stigma and discrimination against persons with psychosocial disabilities. Even those brave enough to attempt to do any form of work concerning them are stigmatised.

This stigmatisation usually comes in the form of the attitude that mental illness is a result of disobedience to the gods. Some even

believe that one should avoid marrying from such family because the curse follows the spouse and his or her family.

Societal Attitude

As a society, what is our attitude on mental illness? Many times we look at it with contempt, uneasiness, embarrassment or fear. We laugh at those who suffer from various mental illnesses. We have a negative attitude towards such people. We even play tricks and mind games on people who suffer from some kind of mental illness. This attitude then makes it impossible for such people to relate with us well.

Many societies in Africa harbour and circulate negative views on mental illness. They use negative words like “crazy,” “insane,” and “psycho” to describe sufferers. Even children learn these names and start using them at a very early age. This attitude results in discriminatory practices and treatment towards persons with psychosocial disability. It creates and perpetuates social inequalities and makes social integration difficult if not impossible.

Media Bias

In its various forms of entertainment, the media depicts sufferers as ugly, distasteful, unwanted, stupid or dangerous. The media also often erroneously portrays mentally ill people as those who commit violence. In most television programmes and films, you often hear people say ‘I have gone crazy’.

I am sure a serious and unbiased study of society would reveal that ‘normal’ people are more likely to commit violent crimes than people with mental illness. The negative image and prejudice against persons with psychosocial disability needs to change. Society should be as accepting when talking about people with mental illness as it is today when talking about people with ‘cancer’ or ‘heart disease’. By changing our attitudes about mental illness, we will pave the way to a better world with more sanity than insanity.

Discrimination in Church

In the Roman Catholic Church, a person with a history of psychosocial disability cannot become a reverend father, or priest. In some cases, they can even terminate the service of a member of a family with such history. This perpetuates the stigma. Because of this intolerance, persons with psychosocial disabilities prefer Pentecostal churches where they are received with love and respect in spite of their disability.

Lack of Information

Another barrier to social integration of persons with psychosocial disability is the lack of information. There is no information for and on persons suffering with psychosocial disability for the general public including families of such persons. People are not given information about their situation and are put on drugs which have damaging side effects.

Those who are hospitalised for example have no sources of information. There is the need for access to television, radio, internet, newspapers and educative films by persons with psychosocial disability.

Public Awareness

Families and the general public need to be informed and educated on psychosocial disability, the causes and the proper treatment available for sufferers. This would help the families to accept their relatives back home and into their communities once they are discharged from the hospitals. This way, rejection and abuse will be eliminated. This could help or contribute to the social integration into the society and church.

Legislation

There is generally poor legal framework for persons with psychosocial disability. Ancient laws that label persons with psychosocial disability as 'persons of unsound mind' are still in our statutes. It is funny because they do not have parameters for defining a 'sound

mind'. This causes legal death and hinders sufferers from benefiting from development programmes run by government. Examples include poverty alleviation, access to loans, participating fully in the open labour market and equally enjoying human rights fully like others.

Legal capacity is an inherent right that is fundamental to the dignity of persons with disabilities. Such people also have the freedom to exercise and enjoy of all their rights. However, legal measures such as interdiction and guardianship prevent persons with disabilities from acting on their own behalf. This must be replaced by a provision for support that does not have the power to override such a person's will but facilitates the exercise of autonomy, as provided for in the Convention for the Rights of Persons with Disability (CRPD) Article 12.

The UN Declaration of Principles on the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care states that it is permissible to deprive an individual of legal capacity by reason of mental illness. It further states that one can authorise a personal representative to make decisions in his or her place. This is contradicted by CRPD Article 12, which requires governments to provide access to support in exercising legal capacity and establishing safeguards to prevent abuse of such measures, in particular to ensure respect for the rights, will and preferences of the person.

The UN Standard Minimum Rules on the Treatment of Prisoners' states that persons found to be "insane" should not be held in prison, but removed to a mental institution. To some extent, this refers to insanity as a defence to imputability of a criminal offence. It is contradicted by CRPD Article 12, which requires the recognition of legal capacity in all aspects of life, and is not limited to civil matters. The provision on removing persons found to be "insane" to a mental institution is also contradicted by Article 14 and 19, which do not permit compulsory institutionalisation based on disability.

Discrimination in Employment

Employment is a major determinant of mental health and a socially integrating force that is highly valued. No single social activity con-

veys more of a sense of self-worth and social identity than employment. To be excluded from the workforce not only creates material deprivation but also erodes self-confidence, creates a sense of isolation and marginalisation and is a key risk factor for psychosocial disability.

For people with a serious psychosocial disability, employment is an important stepping-stone to recovery. It is a normalising factor that provides daily structure and routine. It provides meaningful goals, improves self-esteem and self-image, increases finances, and alleviates poverty. In addition, it opens opportunities to make friendships and obtain social support, enrich quality of life and decrease disability.

People with psychosocial disability who are unemployed and lack meaningful social roles are in a position of double jeopardy. They are stigmatised because of their disability (making it harder to gain competitive employment) and also, they stigmatised for their lack of employment.

Discrimination in Treatment

Several barriers to good treatment for the mentally ill in Ghana do exist. First, there are inadequate service delivery centres. Second, there are few personnel and limited rehabilitation centres. In fact, there is no government rehabilitation centre. The few treatment centres available are privately owned and managed by either churches or nongovernmental organisations. Third, most of the institutions target those recovering from drug addiction. Fourth, financing from government is limited. Most nongovernmental organisations or donors are not interested in mental health because the condition is not immediately life threatening, so they argue.

Self-Pity

Some persons with psychosocial disability also have certain attitudes which inhibit them from integration into the society. Looking down upon one-self and individual abilities is an example of such attitudes.

This is mainly a result of the illness or the stigma and discrimination from society. This is a barrier that hinders the sufferer from reaching his or her potential in life.

Save the Children's fundamental aim in psychosocial programming is to improve children's well-being by:

- (a) restoring the normal flow of development
- (b) protecting children from the accumulation of distressful and harmful events
- (c) enhancing the capacity of families to care for their children
- (d) Enabling children to be active and positive agents in rebuilding their communities.

These are equally true for persons with psychosocial disabilities. There is need to restore the normal flow of the human development, to protect the person from the accumulation of distressful and harmful events and, to enhance the capacity of families to care for the person. The person needs to be empowered to be an active and positive agent in rebuilding his or her community.

There are various aspects of the human development namely the physical, cognitive, emotional, social and spiritual. These are interdependent and reinforce each other. For example nutritional deficiencies can impair cognitive, speech and motor development and functioning as well as cause overall developmental delays; emotional stress can reduce resistance to diseases and cause damage to one's health.

In most communities, the social and cultural aspects of life are intertwined. Cultural norms and values are internalised at an early age. A child receives education from school and other social institutions in order to become a functional member of the society. Children's development – like human development – is a significant part of the process of becoming socially integrated and connected to the wider social world.

Social Integration and the Church

People with mental and emotional illness are part of the church. They make up part of the body of Christ. They are persons baptised, professing faith, participating in fellowship, worship and ministry. They are ministers, teachers and pastors. Others are fathers, mothers, young adults, college students or singles in our churches. Some are our children. Certainly they are part of the community that every church seeks to reach.

Churches that ignore mental illness deny society a valid part of the human story. Many church traditions have no categories for dealing with mental illness. Michael Spencer in his article entitled “The Christian and Mental Illness: the Church and the mentally Ill” told his story as follows:

My father’s depression simply wasn’t allowable in the concept of the church that was nurtured among us. Virtually no one in our church would have felt it was possible to admit to mental illness without enormous stigma. The behaviours and struggles of the mentally ill were interpreted through other grids, from spiritual warfare to personal blame to contamination by worldly influences.

Such phrases as “the victorious Christian life” and “the spirit-filled life” led to simplistic psychologies that made any mental or emotional illness seem quickly “fixable” by prayer, scripture memory and church attendance. As I reflect back on my early years in church, it is plain to me now that many of the mentally and emotionally ill in our church did not seek any kind of help, but populated the altar at almost every invitation. Our pastor, who was completely untrained in these matters, dealt with these people as best as he could. Later on, I was serving in a church in a large urban centre, among a congregation that was much more open about understanding and accepting mental illness as a reality. Even with many “referring relationships” to those providing medical and psychological help, our pastor – a very gifted and empathic man whose preaching reached to the emotions of the

congregation – was overwhelmed with “needy,” emotionally hurting people.

There were often hazards in our ministry caused by the complexity of working with mentally and emotionally disturbed people who expected ministerial staff to be able to help those with severe emotional disability.

Of course, for 14 years I have been face to face with emotional illness on a daily basis. Though our school does not work with “actively” mentally ill persons, we work with many who have “psych” diagnoses and histories. Because we are a Christian community, our staff have differing beliefs about the best way to respond to the needs of our students who have issues in this area. For example, the subject of psychiatric medication is quite controversial, and the topic of Attention-Deficit/Hyperactivity Disorder (ADHD) will always rouse debate.

It is in this environment, however, that I believe I have glimpsed the truth of the Church and mental illness most clearly. My early experience of institutional fundamentalism was unable to cope with the reality of mental illness, but today I look at examples such as Henri Nouwen as signs of Christ moving towards the mentally ill; including them and ministering with them as a sign of the presence of the Kingdom of God.

Nouwen left the ministry at Harvard in order to spend the closing chapter of his life at a community for the mentally and physically handicapped, serving and leading worship for the last, least, little, lost and dying (to use Robert Capon’s list of those Jesus ministered to). I believe Nouwen did this in order to truly experience the church as the people of God seeking to follow Christ in imitation of Christ himself. In Nouwen’s sacramental tradition as a Roman Catholic, there was a strong sense of the presence of Christ in the Eucharist, and the handicaps of those in the Le Arche community provided no barrier to the power of that divine presence.

Those of us who conceive of the church in less sacramentarian terms – but still rejecting transactionalism – can still understand the presence of Christ among the mentally and emotionally ill. That

presence comes as Christ is incarnated in his people, in the Word and in the sacraments. The acceptable year of the Lord is declared among people like this, and God would have them in our midst.

Can the mentally ill receive God's word? Can they participate in the life of the church? But are there limits that must be respected? The answer to all those questions is "Yes." While there are places in the life of the church where emotional and mental illness would mean some limitations or boundaries, the heart of the life of the church – fellowship, worship, communion, service, celebration, love – should intentionally include the mentally ill.

The presence of the sick, the poor and the mentally ill are important reminders of Jesus and his ministry in the Gospels. We cannot make the church a museum of "bright, shiny" people or "catalogue model" teenagers and call ourselves the same movement that flowed from the ministry of Jesus. Mark's summaries of the Galilean ministry of Jesus make it clear that those we would call the mentally ill were there in large numbers. This would not have been convenient, but it was of the essence of Jesus' inclusion.

The church of Jesus Christ should create – or recreate – itself into a form that includes the broken, the sick and the mentally ill. We should be careful that what belongs to Jesus does not come to resemble a country club. This is a serious argument for some of the kinds of "house" church structures that the emerging church is revisiting. The Bible talks about family, marital and personal stability as a qualification for ministry. It seems undeniable that the shepherd cannot shepherd the sheep if he or she is too depressed to speak the truth, love the congregation or feed the sheep.

Mental and emotional illness, however, are not a simple "downers" or crippling instabilities. Many emotionally ill persons function at high levels. It would be foolish to say "Johnny has emotional instability; therefore, he cannot serve or lead." Why? Because such issues are usually not life – dominating. The question is, "How does Johnny live with mental illness – responsibly or irresponsibly?"

In many cases, these afflictions have benefits as well as dark sides. Relentless cheerfulness and glib insensitivity to pain are not

blessings in a minister. A sense of the darker side of life and the reality of pain and brokenness are windows of compassion. Those who read a book like Lloyd-Jones “Spiritual Depression” know they are reading someone who has seen the dark valleys of depressions he seeks to lead the sheep through.

I have experienced this balance in my own life. I have struggled with serious depression and severe, paralysing anger in my own life. At times, these afflictions have hampered my preaching and my leadership, and wounded my family. Yet my family has experienced profound healing. My marriage has deeper strength than most we know. Others see and affirm this. My relationship with my family and my congregation have enhanced the person I am when I stand in leadership and ministry.

These emotional struggles have also made me more willing to share my own life’s struggles with my people – and they unanimously appreciate this and realise that I stand and speak only because of times I have knelt and wept to Jesus. I have been more open for prayer from others. I have taught the value of our own stories. I have an emotional window into the experience of Jesus in dark times, and into his own compassionate ministry. My reading of the Bible is deeper, especially as I read the Psalms. I believe I can enter into the experiences of hurting parents and depressed church members as a shepherd and as a sheep.

As I have written elsewhere, full-time church ministry has amplified some of my own struggles and problems. Looking back, I wish that bi-vocational ministry had been an option in my early years, just as I wish someone had explained depression to me when my father was suffering with it. But I have never been told by any church leader or church member that I was a poor shepherd or a fraudulent minister. I’ve experienced a deep love from my congregations, and I rejoice that some of my struggles have enabled me to stand before them as a person deeply touched by Jesus. My repentance with my family is great, and my appreciation for the grace of God is not academic, but real and personal.

Ministering to and with the mentally ill requires much love and discernment. It is important that ministers and laypersons do all they can to understand mental illness with the best insights of contemporary science and medicine. It is an important witness when we embrace those Jesus embraced, and include those he included. This is why the mentally ill can be a gift to the church, and a continuing opportunity to discover Jesus in those in whom he mysteriously meets us". Now we move on to the final question: What does the Gospel say to the mentally ill?"

Effects of Attitudes and Barriers

It is clear that the attitudes of church and society are damaging to the human development of persons with psychosocial disability making their situations worse than before and also inhibiting the chances of full recovery. A lot of the relapses that persons with psychosocial disability suffer are because of the attitudes of society which are rather disabling. Stereotyping persons with psychosocial disability – that they are always dependant even in decision-making completely kills self determination and personal autonomy.

The Role of NGOs

MindFreedom Ghana is a membership organisation, currently with about thirty registered members. It is an affiliate of *MindFreedom International*. Since the organisation came into being, it has helped raise awareness on human rights and dignity of persons with psychosocial disabilities. The organisation envisages a future where the rights of persons with psychosocial disabilities in *Ghana* will be no longer violated.

The mission of *MindFreedom Ghana* is to offer education in mental health and human rights to the Ghanaian community in order to alleviate the suffering of persons with psychosocial disabilities.

Its main goal is to give people with psychosocial disabilities the control, competence, potential and access to opportunities they need

to change their own lives. Through education, we believe they can improve their communities and influence their own destinies.

MindFreedom is involved in building the capacity of persons with psychosocial disabilities and also helping them find a means of livelihood.

Basic Needs Ghana is another organisation that is involved in fighting for the human rights of persons with psychosocial disabilities. *MindFreedom* has signed a memorandum of understanding with *Basic Needs Ghana* to work together in the fight for the human rights and dignity of persons with psychosocial disabilities in Ghana.

The project with *Basic Needs Ghana* involves outreach programmes to various communities where self-help groups have been formed. Within these communities, we endeavor to build their capacities and empower the individuals so that their voices can be heard.

We have put in place several other activities. For example, we organise a street march every year as part of our anti-stigma campaign. Also, our radio/TV programmes are aired from time to time as part of public awareness. We write articles which are published in newspapers featuring persons with psychosocial disabilities and their plight. Through advocacy, we have also taken issue with relevant government departments on behalf of persons with psychosocial disabilities.

Poverty Reduction Strategy Programme (PRSP) is seen as a way of alleviating poverty among the poor and disadvantaged. *MindFreedom Ghana* believes in a rights-based approach to development. Therefore, we strongly believe that participation in decisions on development that affect persons with psychosocial disabilities is important. Even more important then, their participation is crucial when PRSP is being discussed.

We plan to meet with all the new members and together chart the way forward. We want to find a way to have our voices heard. We also want to give the necessary information to our members so that they can make informed decisions. We also want to empower

our members so that they can be part of the decisions that are made concerning them in the area of medicinal drugs or incarceration.

Other Players

World Network of Users and Survivors of Psychiatry (WNUSP), Pan African Network of Users and Survivors of Psychiatry (PANUSP) and *MindFreedom Ghana* recognise that poverty is about more than just low income. The factors causing poverty and exclusion are wide-ranging. Thus, our work on child poverty covers many areas including education, enterprise, health, justice and communities.

We believe that every child matters, regardless of their family background. Children should have the best possible start in life. We also want to ensure that every young person has the opportunities, skills and support to make a successful transition to working life and active citizenship. Furthermore, we believe that if parents with psychosocial disabilities are helped to take part in income generating ventures this would reduce poverty and exclusion. Their children then can go to school and have a good education. Thereafter, they can be appropriately trained, be employed, hence, break the poverty cycle.

MindFreedom Ghana has a big task to deal with these challenges. We will have to develop educational materials on disability issues such as flyers, posters and banners to be displayed at public places as it has been done in the case of HIV & Aids. So far, this has not been possible due to lack of funds and neglect both by officialdom and the public.

It is the hope of WNUSP, PANUSP and *MindFreedom Ghana* that with the new Convention on the Rights of Persons with Disabilities, things will change. This means that the public should be sensitised and educated in order to change their perceptions and attitudes.

We believe that inclusive educational settings designed to address the individual needs of children offer expanded possibilities for educational, social, and emotional growth among all students.

Conclusion

The family, which is the basic social unit in all societies, plays an important part in meeting the basic human needs of a person. Family support is necessary in psychosocial programming to bring about healing, cure and restoration.

The community – both church and society – also has a role to play. Interaction with and within the community will help rebuild the lives and identities of persons with psychosocial disability. Cultural norms, values and beliefs will have to be changed which will enable them to be able to participate fully in the community. These traditional beliefs and culture influence the behaviour of people towards the mentally ill.

Persons with disabilities – and for that matter those with psychosocial disability – are whole persons with emotions and needs just like all other persons. These persons also have human rights and they need to be treated with dignity and respect as stated in the CRPD.

There must be education and sensitisation of the general public from time to time on the rights of persons with disability as stipulated by local disability laws and also CRPD. There must be some day care centres and rehabilitation centres set up for persons with disability where persons with psychosocial disability could also feel free to go and relax and unwind. It is also good to have peer support groups where persons with psychosocial disability could meet together and be encouraged and empowered. There must be anti-stigma campaigns to change the attitudes of society and church in the various communities. This can help change the negative perception that society has towards the mentally ill.

Questions like: “Have you ever suffered from a mental illness?” found in public service application forms are grossly abused by preventing persons with psychosocial disability from competing favourably in the open labour market thinking. It is discriminatory and should be scrapped.

Stereotyping must be stopped. Livelihoods support programmes must be introduced to persons with psychosocial disability. It is not

everyone who will be interested in basket weaving so it must be more realistic and close as possible to what the person has interest in. Projects must enable persons to become active and meaningful participants in the economic life of their community.

The United Methodist Church says in a script entitled 'We Act in Society' as follows: "Taking an active stance in society is nothing new for followers of John Wesley. He set the example for us to combine personal and social piety. Ever since predecessor churches to United Methodism flourished in the United States, we have been known as a denomination involved in people's lives, with political and social struggles, having local to international mission implications...we affirm all persons as equally valuable in God's sight."

In summary the UN's CRPD has a human rights approach to development, and it is one which:

- puts persons with disabilities first and promotes human-centred development, stresses liberty, equality and empowerment of persons with psychosocial disabilities.
- recognises the inherent dignity of every human being without distinction whether they have psychosocial disabilities or not.
- promotes equal opportunities and choices for all, so that everyone can develop their unique potential and have a chance to contribute to development and society in spite of their psychosocial disabilities
- promotes national and international systems based on economic equity, equitable access to public resources, and social justice.

These are steps in the right direction; it should be embraced as widely as possible and the church must lead in the empowerment of the whole Body of Christ.

Disability, Society, and Theology

CHAPTER EIGHTEEN

The Church and Pastoral Counselling for Disability

David Kiarie

Definitions

Disability is defined as the absence, incapacitation, impairment or dysfunction of certain body organs. These could be internal and invisible such as inability to hear or external and visible like a disfigured limb. The causes may be congenital or non-congenital.

Situational Analysis and Demographics of PWDs

Statistics on disability in Kenya are rare. Without data, it is not possible to determine how disability affects national development or plan for those affected. Neither can they be fully involved in the management of their own affairs. It is only in 2007 that the National Coordinating Agency for Population and Development (NCAPD) with the assistance of Kenya National Bureau of Statistics came up with the first ever comprehensive survey on PWDs. The survey targeted all PWDs including people with chronic respiratory diseases, cancer, diabetes, malnutrition, Aids, injuries from accidents, land mines and violence. They carried out interviews in about 15,000 households.

Findings of this survey revealed that PWDs make up 5% of Kenya's Population. According to projections by WHO, disability affects at least 10% of any given population. Thus at 5%, Kenya seems to be doing better than most countries. This would put the

actual figure of PWDs at about 1.5 million. Of these, only about a third are in formal employment. There is a strong public opinion that developing countries should include persons with disabilities in their development programmes. Also, the levels of literacy and participation in economic activities are low among PWDs.

Among the disabilities, physical impairment was the most common followed by poor eyesight. Nyanza province had the highest number of people with disabilities while North Eastern had the least. The survey also found that more men than women had mental disabilities while more women than men suffered from visual disabilities.

According to the World Bank about 80% of PWDs live in poor countries where they experience social and economic disadvantages besides suffering human right abuses. The World Bank also estimates that for every five people one has a disability (20%). They live with stigma contending with poor policies and other inhibitions that compound their disabilities. The World Bank found a lot of synergy between poverty and disability. Poverty may cause disability through malnutrition, poor nutrition and lower immunisation, lower birth weight, higher rates of unemployment and under-employment.

In March 2008, Kenya signed the convention of rights of persons with disabilities. This is the only human rights treaty adopted by the international community this century.¹ Such treaties should have been signed long time ago. Beyond mere signing, measures should be put in place to fully implement its provisions. Going by World Bank statistics, 20% of Kenya's population has some form of disability. Such a significant part of the population cannot be overlooked or taken for granted.

Perspectives on PWDs

Society seems to condemn persons with disabilities in a manner likely to suggest that they contributed in bringing about the condition. Below, we shall discuss biblical and linguistic perspectives.

¹*Daily Nation*, Thursday

Biblical Perspective

Biblical teachings about disability have been extensively covered in Chapter 1. However, I will cite a few verses to develop my argument. In Jn 9:1-12, Jesus' disciples ask him as to who had sinned so that the man in question is born blind. They pose the question, '...Rabbi, who sinned, this man or his parents that he should be born blind?' The question raises a theological discord. How could the man have sinned before he was born? We later learn from Jn 9:3 that the reason for his blindness was that "The work of God might be displayed in him." God uses people with disabilities for his own purpose.

Do PWDs suffer of necessity because they are the worst sinners? Incidents in the Bible show otherwise. For example, Job's suffering does not in any way incriminate him. "Through all this, Job did not sin nor did he blame God" (Job 1:22). In all this, Job did not sin with his lips (Job 2:10).

In Lk 13:1-5, Jesus draws our attention to those who suffered for no cause of their own. He talks about the Gaileans whose blood Pilate mixed with that of their sacrifices and the eighteen on whom the tower of Siloam fell and killed. Therefore, PWDs are not responsible for their condition. The verses quoted above are supposed to encourage the marginalised, stigmatised and ostracised members of our community who find themselves blamed for their misfortunes. These include PWDs and those suffering from chronic infirmity such as HIV/Aids. We need to acknowledge that these people were created in the image of God. This image is not necessarily physical. Besides, all of us have the right to communicate with our maker, God.

Language Discrimination

PWDs are discriminated even linguistically. In Kiswahili language a deaf person is referred as *kiziwi* while a blind person is called *kipofu*. This is absurd because the KI-VI class of nouns in Kiswahili is mainly used to exclusively denote inanimate things like books. *Ki-tabu* means 'one book' while many are referred as *Vi-tabu*. Why, I ask does disability not take the usual M-class of nouns? If it did, 'a

blind person' would be referred to as *mpofu* while many would be *wapofu* (M-WA class such as *mtu-watu*).

Worse still, the birth of a person with a disability is usually taken as a bad omen. The Kikuyu word for a congenital malformation is *kiugu* – a rather derogatory, condemning and oppressive word denoting helplessness and hopelessness. It is not surprising therefore that PWDs are left uncared for. In some cases they are considered a shameful sight and are locked away or caged like animals.

In some African traditions, a child with a disability would be killed so as to “cleanse” the homestead. Such a birth, it was believed, implied that some calamity or catastrophe would befall the family. Others believed that for a child to be born with a disability, somebody must have be-witched the family. They would then seek the services of a witch-doctor or a seer who would unveil the witch. Others believed that if an expectant mother laughed at a PWD, she would bear a child with disability. Thus, giving birth to a child with a disability was a resultant punishment from God.

Pastoral Care

Pastoral care is the undertaking of a person tending and shepherding his flock. For the church, it is the actual caring for people's needs by either the any dedicated Christian or church staff. The church can do a lot for PWDs in terms of pastoral care. These include teaching, preaching, praying and baptism, bible study and fellowship and worship services. In fact, counselling is part of pastoral care. The church should administer the Holy Communion, visit the sick and offer help to victims of disasters – be they natural or artificial. In these duties, the church must ensure that there is no discrimination for PWDs.

Counselling

Conversely, counselling is the relational process where a trained counsellor guides and facilitates a counselee to make informed choices. The aim of counselling is to minimise, cope or solve a problem or issue. The person who receives counselling is referred to

as a counselee. From this definition, a counselee can be categorised as a person with some form of “disability”. It is unfortunate that, the church seems to overlook people with disability when it comes to pastoral care and counselling. Just like other academic disciplines, disability should be taught under pastoral care and counselling.

The Need for Counselling

Several situations call for counselling. These include death of a loved one, separation and divorce, marriage problems, pregnancy, sex difficulties, trouble at work, retirement and retrenchment. There are also certain stages in our growth when we may need to talk to someone. The most common ones are adolescence and middle-life crisis.

It is generally agreed by all counsellors a person who acquires a disability needs counselling. However, it is the counselee who has the final word on whether or not he or she should receive counselling. Some of the issues that warrant counselling are common for both PWDs and any other persons. However, there are some specific cases for which PWDs require special counsel.

The Process

A counsellor should be non-judgmental, non-perceptive and have a high sense of confidentiality. He or she should give the counselee about 75% of the time to air views in discussion and take only 25% of the time. In most cases the counselee is looking for “a shoulder to cry on”. He or she is asking “can someone listen to me?” “Does anyone care about what I am going through?” PWDs also ask themselves these questions. Pastoral care and counselling should come in handy.

How to Avoid Disability at Various Stages of Human Development

It is expedient to first look at how counselling can be helpful to PWDs in every stage of human development. To some extent it could

even prevent some disabilities. Below, we examine these stages from prenatal to young adulthood.

Prenatal (0-9 Months)

After conception the father and the mother of the expected child need to take great care at the prenatal stage. The mother must attend prenatal clinics for all the necessary check-ups. Proper balanced diet including carbohydrates, proteins, vitamins and mineral salt is of paramount importance. Taking calcium is considerably important for bone formation. That is why some pregnant women develop an appetite for some kind of soil. Calcium tablets can also be prescribed by medics.

However, drugs should not be taken without a doctor's prescription to avoid harming the foetus. In the late sixties, Germany women took Thalidomine to give them comfort in pregnancy. This, they did at the expense of the un-born. The drug made the foetus develop malformations.

Avoid shocks and traumas since they could also cause malformations. The husband should understand the fluctuating moods of the mother. Cordial social relationship at this time should be enhanced. Proper care during the nine months will facilitate the birth of a healthy baby. This care reduces the chances of giving birth to a malformed child.

0 – 2 Years

At birth, the child should undergo clinical examinations to detect any abnormalities and to ascertain that it did not suffer any injuries during the birth process. Any notable abnormalities must be addressed at once.

Breastfeeding is very important because it offers further immunisation. Only a HIV positive mother should be discouraged from breastfeeding to avoid infecting the child. The process of breastfeeding also provides the needed affection. At this stage some habit training is important.

As the child grows, it must receive all immunisations including those against whooping cough, tetanus, diphtheria, smallpox, BCG (against tuberculosis infection) polio and measles. In some remote parts, mothers fail to take children to clinics for immunisation against polio due to long distances. Later, such children became deformed, adding to the population of PWDs.

2 – 5 Years

Healthcare should be continuous at this stage. At this time, the child is active and adventurous. This could lead to small accidents that must be addressed immediately. If not, the consequences could affect the rest of its life. Take care against situations that can lead to accidents, resulting in disability.

Emotionally, children between the ages of two and five years are attracted and attached to the parent of the opposite sex. This is referred to as the Oedipus complex. It is therefore advisable that both parents be available, whether the child is a boy or a girl. This stage is the first preparation for marriage. Children here want to know about the opposite sex, irrespective of whether they have a physical disability or not.

6 – 10 Years (Homosexual Age)

Children at this stage are sensitive to the opposite sex. Boys want to be with other boys or the fathers, while girls enjoy the company of fellow girls or their mothers. To them, feminine and masculine roles in society become more distinct. If proper care is not taken, a child could be fixated and end up permanently homosexual. This is a form of sexual maladjustment.

10 – 12 Years (Pre-Adolescence)

At this stage, the children are about to, or start maturing. In December 2006, I was called to counsel a 26 year old woman whose 12 year old daughter had given birth. Imagine a child bearing a child!

Physiological, emotional and social changes must be addressed appropriately. At this stage, children are very active. The Church

has come up with boys and girls brigade programs. The onset of puberty and preparation for teenage-age are important. Some games for children with disabilities should be put in place. Body exercises are also a must. Proper guidance and counselling must be put in place to help them acquire good values.

Adolescence

This is a wide topic that requires a full chapter. Therefore, I will categorise adolescence into three stages and state the changes that take place at each stage. Adolescents with disabilities are not exceptional. They go through the same stages like all other young people, and so should receive relevant counsel.

Table 18.1: Early Adolescents: Physical and emotional body changes

BOYS	GIRLS	COMMON
• Voice breaking	• Breast develop	• Pubic hair
• Seminal emissions	• Menstruation	• Auxiliary hair
• Broadening shoulders	• Ovulation	• Sexual desire
• Adams apple	• Rounding bones	• Sharp appetite
• Areola gynaecomasia	• Widening hips	• Rapid growth
• Muscle development	• Styria lines	• Self-conscious • Sweat, pimples • Stress, shyness

Middle adolescence (15-18 years): Physical and emotional body changes

1. Difficulty in identity
2. Strong sexual desire
3. Stronger peer allegiance
4. Need for recognition
5. Become argumentative
6. Fashion conscious
7. Need to excel
8. Adventurous

9. Illusions
10. Freedom and enthusiasm
11. Challenge to adults

Late adolescence (19-23 years): Physical and emotional body changes

1. Difficulty in identity
2. Need for formulation of life cycle
3. Completion of career
4. Need for a mentor
5. Hero-worship
6. Future plan anxieties
7. A place in society
8. Chance of a life partner
9. Life confusions
10. Marriage its meaning and purpose

Persons with disabilities are not unique at any stage in their lives. If anything, they need more counsel due to their disadvantageous positions. As teenagers, they oscillate between childhood and adulthood. In the words of David Cunningham of Zimbabwe “A teenager is a between ager”. If any disability is detected from childhood, proper counsel needs to be given to the parents and later to the child. It should be clear that he or she will develop as a responsible person and graduate into responsible parenthood. Such a person needs to be self-reliant to avoid extreme dependency that is by itself incapacitating.

The Church is well placed to cater for the people with disabilities due to their numerical strength which stands at 80% in Kenya. Other factors include credibility, infrastructure encompassing all, pastoral training and having a voluntary captive audience on Sunday and other social functions. The Church has a challenge to use these opportunities to advocate and build capacity for PWDs. I invite all Church leaders and their congregations to integrate PWDs in all their Ministries.

Types of Counselling Required in Maturity

The above discourse focussed on prevention of disability before birth, early childhood and adolescent. This section will discuss pastoral care and counselling at maturity.

Blindness

As indicated earlier, people who lose their sight at an advanced stage in life find it disturbing, devastating and detrimental to personal well-being. Without proper counsel a person may find life unbearable. However with appropriate counsel, encouragement and facilitation one can live a full life.

According to the NCAPD survey, the level of education has direct relationship to socio-economic life of a person. Therefore, a blind person needs to learn how to read and write in Braille. He or she also needs to learn how to effectively use other senses such as hearing and touching. A PWD can succeed in academics by completing primary, secondary and College or University education. A blind person who graduates from University (some with Masters and doctoral degrees) have more opportunities of employment in both the civil service and private sector.

With regard to spiritual life, the clergy should learn Braille so as to teach the blind through the medium. At times, the pastor gives his sermon without due consideration to the blind. To teach the blind catechism, Church doctrine, governance and procedures is of paramount importance. A subject like prayer could deepen the faith of a blind person as he or she learns to talk with the Creator. Indeed we close our eyes when we pray so as to avoid all other interruptions as we talk to God. This is one area when sight is not needed temporarily.

A child who is blind needs to be brought up with Christian discipline. It should be taught the knowledge of God the Father, Son and Holy Spirit who are all invisible. The foundation of Christian life should be based on the stories of creation, men and women of God, and the first and second coming of Jesus Christ.

The blind should not be excluded from these spiritual considerations. Although their lives are affected by a disability, God cares and is interested in their lives. To God, they are his children like any other. In a special way, the blind need to know about God the Creator despite the fact that they cannot see the creation. Seek ways and means to make them visualise creation.

The theology of creation – how the Lord God created the Universe *ex-nihilo* (out of nothing) should be the basis of these expositions as quoted below.

In the beginning God created the heavens and the earth. And the earth was formless and void and darkness was over the surface of the deep and the Spirit of God was moving over the surface of the waters. Then God said let there be light and there was light” (Gen 1:1-3).

Efforts to explain light to the blind should be made especially those whose disability was congenital. Darkness is their ever-present experience. There is need for them to come out of spiritual blindness to spiritual light like any other persons. God moves us out of darkness to his marvellous light (1 Pet 2:9).

The stories of Jesus interacting with and opening the eyes of the blind can be quite encouraging to the blind. One day when Jesus was leaving Jericho, a blind beggar named Bartimeus heard of him and he cried with a loud voice “Jesus son of David, have mercy on me!” When people tried to silence him, he cried out more until Jesus stopped and said, “Call him here”. Jesus asked him “what do you want me to do for you?” and he replied “Rabboni I want to regain my sight” and Jesus said to him “Go your way your faith has made you well”. And immediately he regained his sight and began following him on the road (Mk 10:46-52).

This story has a number of lessons. First, blind people could be reduced to beggars like Bartimeus. Second, the blind man knew Jesus because he called Him by a messianic name (Son of David). Third, the man was persistent despite people’s discouragement.

Fourth, Jesus stopped everything else and invited the blind man to him. Fifth, the blind man was faithful “Your faith has made you well”. Jesus shows uttermost concern for disability and the ostracised. Sixth, the man was not spiritually blind for he knew Jesus. He was a true child of God even before recovering his sight.

In Jn 9:1-2, we read about the blind man who was sent to go and wash his face at the pool of Siloam. He obeyed immediately and received his sight. Questioned by Pharisees about the man who healed him – being a sinner for healing on Sabbath, he answers “I do not know, one thing I do know, that whereas I was blind, now I see”. This episode shows that obedience to Christ yields rewards and that the blind man stood his ground.

The statement of the blind man has led many to Christ, “I was blind but now I see”. This could be the basis of a Ministry for the blind. It is imperative therefore that theological institutions need to come up with theological reflections about the blind. May I suggest three. First, some blind men and women should be trained and ordained as clergy so as to serve congregations. The picture of the blind reaching both the blind and the sighted would be refreshing.

Second, some sighted clergy should be trained purposely for the blind and be equipped for such-like mission. Third, all the Church Ministers should be conscientious on acknowledging the presence of the blind and meeting their needs so as to incorporate them in congregations.

The Salvation Army Church in Kenya should be commended with regard to PWDs is. It runs ‘Institutions for the people with disabilities’ which have helped to uplifts their status in life. The Church needs to care for all the disadvantaged through the compassion of Christ. The Great commission challenges the Church to go and make disciples of all nations (Mt 28:18-20). The word “all” is inclusive, meaning the PWDs are no exception. They need to be included in both evangelism and evangelisation.

Deafness

Just like the loss of sight, inability to hear can be equally devastating. Deafness is even more tricky because it is not visible. At least most blind people can be identified. The deaf have every organ, the ears included – so one cannot tell why they cannot respond. Given proper counsel, encouragement and facilitation, they too can live meaningful lives.

We can use the Bible to counsel people who are deaf. It is written in Lev 19:14 that “you shall not curse a deaf man, nor place a stumbling block before the blind, but you shall revere your God; I am the Lord”. Also, the people with disabilities are so created by God for His own purpose. Ex 4:11 says “And the Lord said to him (Moses) who has made man’s mouth, or who makes him dumb or deaf, or see or blind? Is it not I the Lord?” The verse refers to the incident when Moses was sent to Pharaoh but wanted to decline because he was not to be eloquent. The Lord promised to “teach him what to say”. This shows that even the Lord can teach the deaf how to “hear”. He is concerned because, we read in Is 29:18 that “And on that day, the deaf shall hear a book being read aloud, and out of their gloom and darkness the eyes of the blind shall see”. People who are deaf are not shut out of the Lord’s kingdom. Mk 7:37b says that Jesus made even the deaf to hear and the dumb to speak.

Since deafness is not visible, there are incidences when police harass such people thinking they are rude, arrogant or ignorant. Sometimes, when arrested, policemen beat them assuming they (deaf) are rude by not responding to their questions. The same happens in the case of obeying traffic rules, interaction with others especially in public vehicles. Therefore, people who are deaf should be counselled about public assumptions. Perhaps the best thing to do is to communicate and offer an explanation using sign language. Many people understand non-verbal messages indicating that one cannot hear or talk. The police and members of the public should also be sensitised on the plight of the disability, and as such anyone who does not respond verbally should not be necessarily victimised.

Theological institutions should train pastors and other para-church workers in sign language with a view to incorporating the deaf in church congregations. Alternatively, some deaf people (just as I had argued for the blind) should be trained as pastors so as to serve congregations. Deaf children and young people should be encouraged to study hard and not to let the disability prevent them from attaining a reasonable amount of education. Education will enable the deaf to gain employment and better their lives, to mention contributing immensely to national development. Then, they will no longer to be seen as a liability but partners and equal assets in development. They will easily be integrated in the society, their being deaf notwithstanding.

Disfiguration and Other Physiological Impairments

Disfiguration may come as a result of an accident or disease that changes one's physical form. Such people need counselling so they can accept themselves just as much as before. If no proper guidance is given, such a person may develop a low self esteem. Psychologists have established that, a person with low self esteem is prone to self destruction. They are subject to mood swings, are negative and see themselves as less important than others. They may develop hatred towards the self which could render them helpless, desperate and suppressed.

A case in point is a woman who suffered facial disfiguration after the 1998 bomb blast in Nairobi, targeted at the US embassy. She was taken to hospital and recovered quickly. The family and friends comforted, accepted and encouraged her appropriately. The doctors and nurses did their work. Dermatologists did their best to treat her facial skin. At home the husband and the children were a source of strength and warmth. Despite all these efforts, she did not accept what had happened as reality; she continued to live in self-denial.

While at home one day, she decided to look at herself in the mirror. Immediately she saw her disfigured face, she started screaming and cursing the day she was born. Later she died due to

what doctors described as psychological trauma. After seeing her new face, she was shocked but failed to appreciate what plans God might have had for her.

Other Psychological or Physical Malfunctions

People with other psychological or physical malfunctions generally face exploitation. There are increased reports of rape among women with physical disabilities. The main challenge is that, they cannot stand, walk or even run away from rapists. Some victims are just grabbed, carried into dark corners of the streets and raped. Others who are kept indoors are violated by their own relatives.

In major towns, there are cases where PWDs are dropped in the streets by their relatives to beg for alms and money. Later in the evening, the 'normal' relatives collect them and the day's collection. Instead of relatives assisting them to be better members of society, they use them as a means of earning a living. In most cases, they just allow them to keep a small portion of the alms they earn.

In the recent past, the police have unearthed cases where people with physical disabilities are used for drug trafficking and sales. The reason, many witness, is that people with disabilities are not likely to be suspected by policemen. What they forget is that PWDs are and indeed behave like any other persons in society. The only difference is the physical condition. So, they are caught, just as any other drug-traffickers are netted.

Similarly, PWDs can also scheme, plan, execute or commit crime just like 'normal' people. Thus, due to dire poverty, they may be willing partners in perjury and other criminology. Counselling should target such anti-social activities. PWDs need also to be advised about the consequences of negative behaviour or breaking the law. In any case, the behaviour of habitual drug addicts is in a way a worse form of disability – not to mention the cost involved. PWDs should be guided to strive to earn their living lawfully and in dignity.

Conclusion

“Disability is not inability,” so the old adage goes. In conclusion, I wish to cite cases of PWDs whose lives were or are success stories that should be emulated by all. Many have performed exemplarily, leaving indelible marks on earth. One of these persons is Hellen Keller Adams (1880 and 1968). Hellen is one historical person with disabilities who left a great legacy.

Hellen became deaf and blind due to some illness at the age of nineteen (19) months. Despite these disabilities she did a lot. After learning how to read and write, she got good education and graduated from Radcliffe College, Cambridge (Massachusetts) in 1904. She lectured in many countries and raised money for the education of people with disabilities. *The story of my life* is one of her books, published in 1902. It details her life of 88 years. She is greatly admired as the first PWDs to graduate from university. She has and still inspires many people in the world. She struggled to make people with disabilities economically self-reliant.

In my home country, I will randomly mention three people whose stories are common knowledge. They are not necessarily selected based on any criteria – for I know there are many people out there who have achieved more. However, allow me to mention Mr Kibaya Laibuta, Esther Chebet and Henry Wanyoike. Mr Kibaya Laibuta is a blind golfer who was mentored by two blind men from America. Esther Chebet has no hands. She only has one leg – yet she is able not only to feed herself, but also take care of her child. She washes clothes using only one leg. Also, she uses her mouth like a hand to handle many domestic chores. Last but not least, Henry Wanyoike is blind but a successful runner. He has won many races.

Most of these stories are carried in newspapers, magazines or aired on television stations as features. Perhaps the media should bring out more of these success stories so as to encourage others. Given the right atmosphere and opportunities, PWDs can live like any other person if not better. Without proper counsel and encouragement such people would have remained liabilities who are over-dependent.

PART SIX

Disability in the African Experience

CHAPTER NINETEEN

Persons with Disabilities in Madagascar

Ralphine Razaka

Introduction

With a population of over 18 million people, Madagascar has the highest number of inhabitants in the Indian Ocean. It is also ranked among the poorest countries in the world. The United Nations Development Programme (UNDP) report of 2005 places it at position 146 out of 177 countries. Seventy per cent of the population lives under the poverty line (less than one US 1 \$ per day). Its human development indicator is 0.499 which is an expression of its growing poverty. Illiteracy rate is very high – 30 per cent in urban, and 60 per cent in rural areas. Living conditions are precarious while basic services like healthcare, education, clean water and electricity are inadequate.

Seventy per cent of the total population lives in rural areas despite a rapid expansion of urban centres. The economy of Madagascar has been largely affected by political instability and the energy crisis. According to *Handicap International Project* (2007)) the general poverty conditions are worse for vulnerable groups and specifically PWDs. Such are the economic and social contexts in which PWDs in Madagascar live.

Literature on Disability

Very few books have been specifically written on disability in Madagascar. Most of what is available is from case studies, guidelines prepared or Projects written either by *Handicap International* or by associations of PWDs. Information on the situation of PWDs is very limited. No statistics are available.

Traditional Beliefs About Disability

However, disability is not a new concept to the Malagasy Community. Traditional songs and tales on PWDs prove this fact. According to traditional beliefs, having a PWD in a family was shameful. It was thought to be a curse. To escape such a 'curse' the family had to perform a blood sacrifice which at times involved killing the PWD so as to remove the 'curse'.

Other communities believed that PWDs happened where either parents or a family member had sinned, offended or annoyed the ancestors hence the 'curse'. The 'disgrace' of having a PWDs was sometimes extended to the whole community. Moks Razafindramiandra (1994) in his book *Le faravavy malemy* tells the story of a physically disabled girl who was abandoned by her parents. She later managed to succeed alone in her life

Traditional people of Malagasy were very suspicious of any unusual happenings – even without disability. For example, the birth of twin babies in some parts of the island especially the South East is still considered abnormal. There are only three options for such children: they have to be killed, be thrown away or, at best be given to two different persons to nurture them. The Malagasy ancestors also believed in astrology. Any baby could be put to death if the day it was born was considered "bad". It largely depended on their whims since there were no laws defining what a 'good' or a 'bad' day was.

These beliefs and practices cannot be supported by any theological or scientific theories. They only help us to understand how our traditional communities treated PWDs with contempt. Their concepts, mentality and behaviour towards disability and especially PWDs were utterly contemptuous.

Medical Definition of Disability

The World Health Organisation (WHO) defines disability as any partial or total deficiency of a physical or mental organ(s) in a person causing a permanent loss of the function of the organ. However, this definition is incomplete. To understand disability as a whole, we need to add other dimensions such as social, environmental, political and gender factors.

Law no. 97-044 (dated February 1998) on rights of PWDs in Madagascar recognises that the concept of disability is based on a medical understanding. In this law, it is clear from the definitions of disability and all the given provisions that those who conceived it considered only the medical dimension. Compared with the traditional understanding of disability as argued above, the medical dimension is an important evolution in ideology.

The details of many medical definitions of disability lack precision. Those who attempt to define the term fail to clearly differentiate impairment, deficiency and disability. In my opinion, impairment indicates any partial or total failure in the physical or mental constitution and functioning of an organ or limb in a person's body. Deficiency on the other hand is the result of the impairment which prevents the person from performing usual activities. Lastly, disability is the experience PWDs face from society like isolation and exclusion.

Social Definition of Disability

The medical definition of disability does not recognise the social dimension. It ignores the negative impact of exclusive mentality of the society towards PWDs. The social dimension adversely affects the personal development of PWDs. To better understand disability and PWDs much still needs to be done in terms of public awareness.

It is only now that the Malagasy people have started understanding the social dimension of the disability. For long time, they did not consider its impact on the lives of PWDs. The environment especially in rural areas is not very conducive for PWDs. Those who are able to move still experience difficulties. The milieu

often presents obstacles such as manoeuvring across rivers, forests, mountains and valleys. Although surfaces are uneven, no attempt is made to make it easy for PWDs to move easily. Therefore, is not easy for PWDs living in a natural environment.

In towns and urban centres the situation is not better. The built environment does not address the needs of PWDs. Worse still; there is no urban development plan. Also, all legislations related to buildings and constructions do not mention the needs of PWDs. It is such that all administration, public and private buildings, private houses, public transport and other places have ignored accessibility norms for PWDs. According to *Handicap International* (2007) PWDs encounter high steps, narrow doors, inaccessible or no adapted toilets or no toilet at all everywhere they go.

For the last two decades awareness about the plight of PWDs has risen, thanks to sensitisation and lobbying by DBOs. However, by international standards, these results are still very slow. Much has to be done before Malagasy people understand that disability has three dimensions, medical, social and environmental.

True Causes of Disabilities

Apart from superstitions and false beliefs discussed above, the causes of disability in Madagascar are closely linked to poverty and ignorance. When asked about the causes of disability, the frequent answer is “We don’t know.” Parents of PWDs too often feign ignorance and will not seek to understand the causes.

Many Malagasy people do not observe proper hygiene, and have no access to adequate healthcare. The alimentation of pregnant mothers sometimes lacks the necessary vitamins for the foetus to develop well. This may lead to birth of children with some form of deficiency. Thus, preventive measures such as vaccines are unknown and not practised especially in rural areas. In case of actual illness, many people cannot afford to buy medicines. Therefore, no special care is given to health conditions in general and to pregnant mothers in particular.

Low living conditions constitute another factor that impacts negatively on the health of Malagasy people. Madagascar belongs to the group of developing countries whose economies are not flourishing. Healthcare is therefore not a priority in government expenditure or the people themselves. People are basically just struggling to survive. Since food security and shelter is a big problem, they have to choose between spending money on medicines or starving. Women, especially those in rural areas cannot afford to go to hospital to give birth, leave alone attend antenatal clinics. They mainly rely on help from traditional practitioners. This is not safe both for the mother and for the baby. Unfortunately, this neglect and resulting accidents is one of the causes of disability.

There are also cases where people are born with disabilities due to inheritance. However, such cases are not widespread. Children are born with different types of disabilities.

History of Disability

Before the establishment of colonial rule in the 18th century, missionaries from different Christian faiths competed in setting stations in Madagascar. Catholics and Protestants sought to dominate Madagascar and were aided by France or Great Britain who held different political positions.

In colonial times, PWDs were provided with limited special care. For example, a specialised centre was built for children with poliomyelitis inside a hospital complex in the same town where missionaries set their stations. Work in the centres for the blind and for the deaf went on well. To this day, these separate educational centres teach Braille and sign language. Children are also taught handicraft such as sewing, embroidery, knitting and woodwork. They are also taught Christianity.

Callet (1878) argues that missionaries provided social amenities to win locals. They convinced locals that they were out to bring civilisation to the Island and had their interest at heart. Therefore the Christians built schools and hospitals in places where they established stations. Missionaries, particularly those from the

Lutheran Church of Norway founded schools for the blind and for the deaf. These institutions were owned by their religions and were the first official centres to take care of PWDs. They were located in the central part of Madagascar in Antsirabe¹.

Therefore, the concept of disability evolved around this time due to Christian influence. Instead of parents killing babies that were born with disabilities, they started believing in medical treatment. In this period, the understanding of disability was still very limited in Madagascar. Thus, society simply undermined them.

For a better understanding of the social concept of disability, we need to know the characteristics of Malagasy people. First, majority of the people are very empathetic. That explains why they felt pity for PWDs. The consequences of their reaction differed from one individual to another. Parents, siblings and other close family members thus, overprotected PWDs amidst them. Other people's reaction to PWDs was demeaning in a way. They looked at them as useless, persons without any ability who were condemned to beg. The Malagasy society was not very literate. Therefore, it was very difficult for them to understand the medical origins of disability.

When some people speak about mental disability, we notice feelings of fear. This reaction is based on the lack of knowledge about PWDs. Again, this situation can only be seen from the perspective of the deeply rooted idea that a 'bad' spirit causes disability. Aptly, the people adopted a defensive attitude because the causes of disability and contagion were not clear to them. They even did their best to avoid contact with PWDs.

Malagasy people in general lack awareness about disability. There are no good practices on handling PWDs even from the administration. Only few people are aware about disability for the only reason that it affects a family member or a close friend. The

¹Antsirabe is a city about 170km of Antananarivo in the South. It hosted the educational Centres created by the Norwegian Missionaries for deaf and blind children. The Centre for the treatment and equipment for victims of poliomyelitis was also set there.

sad thing is, during elections, the plight of PWDs is used as political propaganda – promising PWDS social actions in plans and manifestoes. Once the elections are over, none of the promises are fulfilled. PWDs and their struggles are soon forgotten.

Types of Disability and Actual Situations

Several types of disability are found in different regions of Madagascar. They are generally spread in an equal way. No single type is dominant or can be associated with a specific region. We will look at each of the types in the context of Madagascar but with a worldwide view.

Physical Disability

Majority of PWDs in Madagascar have physical disability. They are quadriplegic, have a ‘bad’ upper hand or lower limb. The most common cause is polio which leaves the person unable to fully or partly use either limb. This deficiency affects the person’s mobility. The person cannot walk well without assistance or equipment like crutches. Others are left with no alternative but to creep or crawl.

Another form of physical disability is the club foot. Although the disability directly affects the feet, the consequences on the person’s mobility are limited. Even though the number of persons with club foot is not as high as those affected by polio, this condition is still disabling.

Spinal bifida is a condition of the spine that some people are born with. It often makes them unable to use their legs. This condition is not widespread in Madagascar. But, persons with hunchbacks and dwarfs are more common. Indeed, words such as “hunchbacks” and dwarfs are offensive, but unfortunately, that is the way such conditions are stereotyped. Other PWDs include those with cerebral palsy and epilepsy. Such PWDs are feared because they are mistaken for the mentally disabled.

In general very few specialised centres are available for persons with physical disability in terms of treatment equipment and education. Catholic missions provide treatment services and equipment in some

towns in the different regions. But, both the facilities and services are inadequate.

The main problem facing persons with physical disability is mobility and accessing buildings. Since they cannot move about freely without assistance, they are forced to depend on the goodwill of society for support. This condition has denied them a fundamental human right – that of movement. This category of PWDs has limited social contacts because they are isolated and excluded from mainstream society.

Mental Disability

Mental disability is very complex because it is very difficult to measure the extent of its impact on a person. But, we know that it can affect part or the entire brain. Though its manifestation varies, it also depends on the degree of the disability. Sometimes, its appearance can be a danger for the society in extreme cases. The origin of mental illness is hardly known and very few specialists seek to determine the cause. Also, society rarely attempts to distinguish between a person who is mentally disabled and a person who is foolish. Centres that can host or treat mental illnesses are scarce. Otherwise few public centres are available in the field of mental disability which is rather treated in the neurology services. Many persons with mental illness loiter in the villages or in the streets of towns. As stated earlier, they either cause fear or are ‘objects’ of fun and amusement.

Religion is very important in Madagascar. Churches therefore show their responsibility to PWDs by organising revival movements and camps to ‘treat’ diverse illnesses including mental disability. The treatment offered is mainly through prayers and exorcising evil spirits. Protestant Churches are the most forthright through a special group

of persons they call “shepherds”². Of recent, the number of revival camps has drastically increased.

The main problem for persons with mental disability is at the family level – especially if the problem is profound. The PWD is largely dependent in all ways and requires permanent assistance. There is no motivation to educate or send such a person to school since eventually, he or she may not be able to do any type of job. Thus, mentally disabled are isolated from the rest of the society. Normally, a lot of misunderstandings exist between ‘them’ and ‘us’. More often they are in the end abandoned by their family to their own fate.

Visual Disability

According to the United Nations estimations, 10 per cent of Madagascar’s population suffers from some form of visual impairment. Apart from the totally blind people, the figure includes people with many other eye problems especially in rural areas. This figure corroborates with that of the federation of blind people in Madagascar. Of this number, only 3,000 are educated. In some cases, some children are born with visual impairment.

People with visual impairment have benefited from the educational centre set up by the Lutheran church as earlier mentioned. However, the centre is not accessible to blind people from remote regions. The Lutheran church is making efforts to create more centres in some of their main synods. Since synods are spread in different regions of the country, it will mean increased access by PWDs.

Meanwhile problems caused by visual disability remain crucial. Many can hardly afford even the most rudimentary equipment

²Shepherds are persons from the group of revival movement in the Church. They received special theological training for two years and they can assist the Pastor in his tasks for example in the sermon and specifically in spirit healing. Revival camps are created through Madagascar to host and care for many illnesses among them mental disability which is considered as an evil effects. Shepherds are working in revival camps.

required for his mobility – the white cane. The few who have white canes are given as donations or from part of projects. Similarly, the government does not provide free white canes for PWDs. More seriously blind children do not attend school since the education programme is not appropriate for them and trained teachers are very rare. Also, they need assistance to and from school. Few adults attend the Lutheran school and use machines to read and write Braille. However, they cannot afford to buy their own machines since they are very expensive. Likewise blind people are also victims of isolation and exclusion. They remain dependent for their mobility.

Hearing Impairment

This group includes the totally deaf and those with hearing problems. It is difficult to estimate the number of people affected by this disability. The Norwegian Lutheran mission has also built an educational centre for deaf children, near the centre for the blind. Sign language is taught as well as handicrafts like embroidery, knitting, cooking and woodwork. The Lutheran Church continues to give support by building more educational centres for the deaf in its synods located in various parts of Madagascar.

The main problem is how to train sign language translators who can in turn teach people with hearing impairment. Opportunities for training are very limited due to its cost. Without sign language translators, deaf people are totally cut from the rest of the world. They cannot hear and participate ably in what is happening, despite easy mobility and access to buildings. Also, even if they can see, they cannot understand what is discussed in any meeting. Since communicating with deaf people is difficult, they lack access to information.

PWDs in Madagascar and Their Rights

In Madagascar, the situation of the rights of PWDs is far behind compared to other countries even some on the African continent. The main reason why PWDs do not enjoy same rights and freedoms is ignorance. Very few PWDs know about their rights. It is strange

that even though the legislation on the rights PWDs was passed by Parliament over ten years ago, it remains unknown to many PWDs. Even professionals in areas such as the Departments of Population and Social Affairs, Health, Education, Justice and Labour have not internalised this piece of legislation. No wonder, no effort has been made to disseminate its contents through workshops, seminars or training. To this day, very little attention is paid to the rights of PWDs. As a result PWDs do not receive proper healthcare and facilitative equipment. Very few children with disabilities attend school and young people receive little professional training. Job access is restricted leaving many adults with disabilities economically dependent.

Policy on Disability and DPOs

For a very long time, Malagasy political leaders did not care about disability. As stated earlier, only religious missions like the Lutheran and Catholic churches were involved in disability work. In the colonisation era, only two institutions were built – one in Antsirabe for children with physical disability and another in Antananarivo for equipment for physical disability. Nothing was done for the other disabilities. Therefore, PWDs who were not admitted to homes for care were left as a burden for their families.

After independence in 1960, disability was not given priority by new government. No measures were taken to address the plight of PWDs. The little work done to alleviate the suffering of PWDs was by associations of Disabled People's Organisations (DPO). In first three decades, political leaders only paid lip service to disability. Very few people were engaged in the field of disability and it remained largely unknown.

It is only in the last two decades that the government has shown real concern for PWDs. The Bill, Law no. 97-044 that governs the situation of PWDs in Madagascar was passed by Parliament on 02 February 1998. DPOs participated actively in the preparation and publication of the laws. They continued in their efforts and ensured that decrees and by-laws related to this legislation were published in 2001 and 2005 respectively.

Unfortunately, there is still a large gap between the existing legislation and what is happening on the ground. Application of this law to bring positive change to the lives of PWDs has not been felt. No funds have been made available to support programmes that can raise the living standards of PWDs living. We still lack a human resource base that is specialised in disability and can convince the political leadership to mainstream disability in all government programmes. Also, participation of PWDs in politics is limited for obvious reasons, the main being illiteracy since schools are inaccessible to them.

The second impediment is the attitude of society which fails to recognise that PWDs have the same rights as anyone else. Political affairs are not considered to be a business for PWDs. In addition, no eminent persons have attempted to influence political leaders to acquaint themselves with the vision on disability. As a result Madagascar does not have a policy on disability. The consequence is that PWDs and DPOs are not allocated financial resources in the national budget.

In the 1980s disability was placed under the Department of Population and Social Affairs. This was a small Department which had several other functions. Its mandate and duties included Family, Gender, Children and Social Protection among others.

Despite this setback, the creation of this Department was a step in the right direction. With the help of *Handicap International*, the Department started setting up branches of the equipment centre in the six former provincial capitals and other regions. Later, these centres experienced lack of human and financial resources as well as raw material. Although PWDs expected improved services and specifically equipment, the centres were not very helpful.

Recently, government ministries were restructured. The Department of Population and Social Affairs has now been made a department in larger Department of Health. Under this structure, it means disability has been somehow downgraded. Therefore, PWDs cannot expect that their voice will be heard since the government

continues to treat disability as if it is not a priority. Now it is just a small element in the “big machine”.

Other problems included lack of specialised service provision related to the needs of each type of disability. PWDs do not have access to basic social services such as clean water, electricity, healthcare and public transport. The main reasons of such exclusion are mainly poverty, mobility problem, misunderstanding and lack of awareness.

Disabled People’s Organisations

The formation of Disabled People’s Organisations in Madagascar started in the 1970s. Realising that they cannot expect much from the state PWDs understood early the need for them to form such associations. They were probably alive to a Malagasy proverb that says “those who separate are like sands while those who join each other are like rock”.

The first group of PWDs to form an association were supported by parents and friends. This association known as *les Orchidées Blanches*³, literally the White Orchids brought together persons with mental disability. In 2007 it celebrated its 35th anniversary: Many similar associations were founded later in the different regions. They have now formed an umbrella Federation called the Federation of Persons with Mental disability in Madagascar.

Persons with other disabilities like physical, deafness and blindness also formed specialised associations themselves and also formed umbrella federations. We have six federations of PWDs which are also recognised by the state. Four of them are specialised. They bring together persons with deafness, blindness, mental disability and handisport. The other two federations are open to all PWDs. The difference between the two types of federations is in their objectives and activities. Specialised federations focus on creating

³ Les orchidées Blanches was an originally association . Latter a Centre with the same name was created for the education of children with mental disability.

job opportunities for members. They have a sewing workshop which produces boiler suits, gowns and uniforms. The objective of the others is to promote and protect PWDs and is engaged in the struggle for their rights and freedoms.

Another DPO is the National Committee for the Decade for PWDs. It is inscribed in the African Decade for PWDs and has been in existence in Madagascar since 2003. The Committee is composed of representatives from the Health Department and other Departments affected by disability issues such as Education, Labour and Training, Justice, Transport, Sports and Culture. The six federations are also represented in the Committee. However, non-disabled members out-number those with disabilities. Since its formation, the Committee started by defining terms and explaining disability concepts because many of the members were ignorant about them. Before drafting an action plan, major political upheavals occurred in the government which delayed the process.

The federations of DPOs are involved in the human rights movement. This involvement is based on their assertion that PWDs are human first and then PWDs. Knowledge and activities related to human rights are basic to the rights of PWDs. In 2006, Collectif des Organisations des Personnes Handicapées⁴ (COPH) together with various groups of human rights participated in the elaboration of the Shadow Report from Malagasy Civil Society about Civil and Political Rights. The report contains clear paragraphs on the situation of PWDs in Madagascar. This Shadow Report was given to the

⁴COPH with its 140 association members spread over 18/22 regions of Madagascar and is the most important federation of PWDs. Though it is not the oldest, created in 2000; it is very dynamic and deals with many actors. Its main activities are focussed on the development of capacity building for the basic associations, the promotion of communication and the empowerment of the members in taking their own responsibilities. COPH recently launched its web site www.handi-gasy.org but still in National language the Malagasy.

United Nations High Commissioner on Human Rights in Geneva in September 2006 and was defended in New York in February 2007.

In 2006 with the help of *Handicap International*, the federations of DPOs organised to send a representative to the 8th *ad hoc* United Nations Committee in New York for the elaboration of the final text of the International Convention related to rights of PWDs. Afterwards the six federations decided to set the Platform for implementation of the whole Convention in the country and a follow-up mechanism. In September 2007, the government signed this Convention. This is not sufficient. The Platform of DBO federations is determined to push the political leadership to ratify the convention. To this end, a project has been written together with *Handicap International*.

The Platform of the federations of DBOs is also part of the National Organisation of Civil Society as an active member. This relation accentuates contact with international institutions such as the European Union (EU), United Nations Development Programme (UNDP), and World Bank. The federations of DBOs are given opportunities to develop their capacities through financial support and also improve their income generating activities through workshops and trainings.

Though mired in some problems, the Platform of federations of DBOs represents a good initiative to confront government inaction or slowness. The main problem is to internal organisation.

The Platform is not formally set because members have failed to agree on a common action plan. The only agreement reached is on the International Convention on the rights of PWDs. Other difficulties include individual interests, selfishness and leadership conflicts in the federations. The Platform also lacks financial resources.

However, all is not lost. Apart from the weaknesses discussed, DBOs have many strengths. They constitute the expression of common initiatives to respond to the needs of specific disability groups. They operate within the law, are formal with status and individual internal regulations. Their leaders are elected in a

democratic manner. They collaborate and partner with the state and other NGOs. Through specialisation, the organisations have encouraged distribution of tasks.

Although the weaknesses may be many, DBOs have done a good job. Investing in literacy programmes for PWDs can help improve the management of DBOs. Instead of members depending on initiatives taken by their leaders, they should be taught about DBOs, their aims, functions and common interests. They should know about the financial systems and master the procedures for applying for funding. Also, they should learn administration and prudent financial management. With this knowledge, ordinary members can contribute in formulating objectives and action plans.

Disability and the Church

Traditional believes is widely practised and is the dominant religion in Madagascar. This is followed by Christianity the Islam which is predominant in the North West and the South East. Whatever their religion, Malagasy people are deep believers and practise religion seriously. They also apply religious instructions in their day-to-day lives. Religious practices and beliefs have an impact on social life in Madagascar and especially on the way people view PWDs.

Christian Church Organisations

The Christian communities are mainly made up of Catholics and Protestants. Other Christian denominations include Adventist Church, Pentecost, Baptist and many others. The National Council of Christian Churches (FFKM) is the national umbrella organisation. It also has a presence in the regions. Members include only the main Churches such as Catholic, the Presbyterian, Lutheran and Anglican. Even though membership is open to other smaller churches.

FFKM has various Ecumenical committees that address different socio-economic and political sectors the nation. Christians from different churches participate in these committees. Christian churches express their opinion on issues of national importance

through these committees. Christians, through the committees make their stand known on education, health, gender, development, the media and the political life of the nation in general.

Government and other agencies consult the FFKM's national bureau on issues of national importance. Most of the time, its opinion can influence policy. In the historical evolution of the country, political leaders have constantly sought help from Church leaders. This is because Malagasy people respect religion. In few cases, it is hard to distinguish between the powers of the State and those of the Church.

Another Christian organisation worth mentioning is the Union of Protestant Churches of Madagascar (FFPM). This was formed by the Presbyterian and Lutheran churches at both national and regional level. The two Churches work together in theological fields such as Sunday school, Youth movement, Women and Men Organisations, and Revival. They also have common structures in social services like education and communication. However, the identity of each church is maintained.

It is sad to note that despite the influence of the church, disability does not appear on its agenda. Even in Church, the leaders do not regard disability as a social concern that is worth discussing. Though Catholic and Protestant missionaries were inspired to found specialised centres for PWDs, one can be forgiving for thinking that this was out of pity. By isolating PWDs in special centres and homes, the church too is guilty of exclusion and isolation

Incorporation Within the Church

The number of PWDs who belong to the Christian community is almost negligible. They face a number of challenges. First is access because most churches in the country are situated on top of hills. Second, the churches are constructed without considering how PWDs can access them. Many PWDs are therefore reduced to beggars because of poverty alluded to earlier – a status that gives them a bad image in the eyes the church.

While the issue of disability is now in the public domain, few churches are willing to make adaptations to cater for PWDs because

they consider it costly and unaffordable. An alternative is to create prayer cells in homes of Christians which are (homes) accessible. It would encourage PWDs to share the word with other Christians.

The concept of “Church of all and for all” developed by EDAN is yet to be realised among the Malagasy Christian community. PWDs do not participate actively in the Church life. They are not accorded any responsibility because they are thought of as being incapable. It seems as if they are just there to feed on the Lord’s words. For example, even if a blind man is able to play a piano or organ, his talents are rarely acknowledged. The needs and suggestions of PWDs are rarely taken in account. When it comes to church leadership, the effort to let democracy play out seems to be limited to special groups like women and youth. This does not necessarily include or recognise PWDs as a special group. Such practices are really frustrating.

Old Testament Construal

Malagasy Church seems to approach disability from the perspective of the Old Testament construal. For example, it is written in the Old Testament that an animal without blemish should be used for sacrifice. From such a detailed account, we can only conclude that perfection is the norm and that God’s Holiness does not allow imperfection. Related to sacrifices is the issue about priesthood. This is worth mentioning because it is written that persons with defects are not allowed to approach God’s altar (Lev 21:16-23). Since this is the practice in Madagascar, we can only conclude that the verse is taken literally and has an exclusive meaning. This kind of practices impact PWDs negatively by denying them access to the priesthood. Some churches even exclude women from priesthood for no other reason but their physiological being (Lev 15). As a result, there are very few priests in the Malagasy Church who are women or PWDs. To cap it all, main Christian Churches are reluctant to openly discuss this issue.

As an exception, the Presbyterian Church is open to modernity and accepts women as priests unlike Catholic and Lutheran Churches

where priesthood is still restricted to men. However, PWDs are yet to be accepted as priests.

Among Malagasy people, any person who exercises any form of power and has a leading role is called “*raiamandreny*” which literally means ‘father and mother’ or ‘parents’. This is a great honour because parents play a special role in social relations. This term is used to refer to among others, traditional leaders, teachers, politicians, technicians, soldiers and even priests. We can see that the notion of ‘parents’ extends beyond the biological sense and applies irrespective of age. “*Raiamandreny*” are expected to have outstanding behaviour and demeanour. Thus, although the perfect physical body is not expressly mentioned as a pre-requisite for one to be called “*raiamandreny*”, it seems that is the case when it comes to PWDs. Since the term is not used in reference to PWDs, the traditional understanding of “*raiamandreny*” does confirm the perception of the Malagasy Church about PWDs, hence their denial of access to priesthood.

The New Testament Approach

The New Testament approach to disability is seen through parables from the gospel where Jesus healed various PWDs. These stories seem to support the concept of teaching people about patience, keeping faith in God and believing in His mercy. This perception by the church fails to address disability as a social concern where we all have a role to play. For example, for the paralytic man to be healed, his friends dropped him from the roof (Mk.2:1-12). It is evident that the scripture does not emphasise the role of the paralytic man’s faith or insinuate about that of his friends. This means the only positive role that PWDs can play is just to believe and keep the faith.

We can also infer that since no mention is made on whether or not PWDs directly participated in the spread of the Gospel, the Malagasy Church has borrowed a leaf by failing to encourage PWDs to actively serve the church.

An unfortunate incidence took place in a church in Antananarivo that shows the negative attitude towards PWDs even in Church.

Through an initiative of Norwegian Missionaries, the Lutheran Church continues to assist PWDs. It has built a Centre for deaf children next to a big Church. Deaf children normally have their Sunday services in a chapel inside the Centre. Their pastor uses sign language. One Sunday, the children were brought to the big Church so that they can socialise with the other Christians. The pastor came along to translate the service for them in sign language. As the service was going on, the Christians complained that the pastor's gestures were disrupting their concentration. He had to stop and since then, the children have never gone back to that church.

Personal Experiences

In my childhood the notion of rights for PWDs had not yet developed in Madagascar. I attended a normal school with other children. There were no special measures taken to suit my condition. I had to adapt myself to the system. Apart from usual steps, I did not have much difficulty. Since we lived in town I did not have to walk too far to reach school. The other children were not comfortable having a PWD among them. They therefore did not know how to deal with me. They were not particularly aggressive but I was always the one to take the first step to establish friendship. My colleagues seemed to be embarrassed. I had to struggle alone. From an early age, I started to advocate for my own person by explaining what I knew about my disability, how I felt and what my needs were.

By this time there was no training for PWDs and definitely no DBOs. Also, information on disability was available. I struggled to improve my communication skills and persuasive capability by reading widely. I had to grapple with issues like social approach, searching for a job and facing my in-laws to be. This situation was not only mine, but also faced all PWDs of my generation. We learned to live life without guidance or direction. The experience was not easy. It was emotionally difficult.

Although my parents and siblings had no special training on disability I benefited because I got a very good education. They always looked at me the same way as the other children. For example,

since we were many in the family, we had to share chores at home. I was in charge of the ironing clothes. We lived in the town where the only centre for children with disabilities was situated. Whenever I was unwell, they took me there for treatment.

However, I was never prepared psychologically before I entered the society. I had got tertiary education and taught in a high school for a long time. Some misadventures happened in terms of job relations but I managed it alone as usual without external support.

I grew up in a Christian family. This upbringing was not interrupted even when I was in the treatment Centre because catholic priests and protestant teachers ensured that I got regular services. We took bible studies where I was taught very early to share my knowledge with small groups. It was the first occasion for me to teach Sunday school. I continued with the habit in my youth. As an adult, I decided to train, become a shepherd and be more active in sermons and healing souls. At the beginning some people appeared reluctant to accept me as a shepherd. Since I was determined, I managed to succeed. In the meantime I also studied Theology for lay persons in a FFKM Institute for two years. At the end of the studies, we were asked to write a dissertation each on the theme of our choice. I chose "*Persons with Disability taking their responsibilities in the Church*". I made a brilliant presentation on the subject and received very good approval.

I made every effort to put in practice what I had written in my dissertation. When elections were called in my Lutheran Church, I vied for a position. Of the 70 candidates required as members of the Church Committee, I was number 14. I had won. Further, as a member of the Committee, I was elected as one of the four secretaries in charge of announcements during Sunday services. I was also among the founder members of a branch of Working Women Organisation.

Conclusion

My personal performance was motivated by challenges facing PWDs and the social and Church reactions. Most of the initiatives I took were because of personal inspiration. There was no guidance, and theological or pastoral support. No DBO is rooted in the Church yet many members are Christians. Because of early history, it is very difficult to reorient them to any church based organisation.

The situation of PWDs in Madagascar is still very difficult. The general understanding is based on traditional beliefs which consider disability as a curse. Medical treatment, equipment, inaccessibility, public assistance and other infrastructure for PWDs are still inadequate. Through their own efforts, PWDs have set up associations, federations, organisations and a Platform. These DBOs have played and continue to play a crucial role in advocacy and lobbying for rights of PWDs. They have made attempts to collaborate with public and private sectors and with the international community.

The theme of rights for PWDs progressed since the legislation was passed by Parliament over ten years ago. The country has also acted in favour of United Nations International Convention related to the rights of PWDs. The President signed the Convention but the ratification process did not start. However, PWDs are yet to feel any positive impact in regard to the national legislation. PWDs are yet to be fully integrated in the Christian Church. Many Church buildings are not physically accessible. Priesthood is still elusive for PWDs. These are some of the issues that Malagasy people need to address so that PWDs can take their rightful place in society.

CHAPTER TWENTY

Persons with Disabilities in Malawi: What are the issues?

Rachel Kamchacha Kachaje

Introduction

Malawi is a landlocked country in the south-eastern part of Africa. It borders Zambia to the northwest, Tanzania to the north and Mozambique to the east, south and west. The country measures 119,140 square kilometres of which 20 percent is covered by water bodies.

Established in 1891, the British protectorate of Nyasaland became the independent nation of Malawi in 1964. After three decades of one-party rule under President Hastings Kamuzu Banda, multiparty elections were held in 1994. The foundation for the new era of democracy was elaborated in the 2004 Constitution of the Republic of Malawi. To achieve participatory democracy, the Decentralisation Act was passed by Parliament in 1998. This Act gives districts political and administrative authority so as to enhance a strategy for realising the country's development goal of poverty reduction.

The economy is predominantly agricultural, with about 90 per cent of the population living in rural areas. Agriculture accounted for nearly 36 per cent of Gross Domestic Product (GDP) and 80 per cent of export revenues in 2005. The main challenges facing the

government include developing a market economy, improving educational facilities and tackling environmental problems. Other problems of major concern are increased corruption, population growth, pressure on agricultural lands and HIV & Aids.

Ministry of Persons with Disability and the Elderly

Traditionally, disability issues were placed under the Ministry of Social Welfare. PWDs lobbied the government to move disability issues from the Ministry of Social Welfare to the Office of the President and Cabinet. This they did during celebrations to mark the International Day of Disabled People on 3rd December 1998. In response, President Banda who was the guest of honour directed that a Ministry for **Persons with Disability** be established with immediate effect. So in December 1998, the Ministry for Persons with Disabilities was formed. Seven years later, issues of the elderly were added to its portfolio. It is therefore called the Ministry of Persons with Disability and the Elderly.

Malawi Council for the Handicapped (MACOHA)

Malawi Council for the Handicapped (MACOHA) is a parastatal through which the Ministry Responsible for Persons with Disabilities and the Elderly implements its programmes. MACOHA's aim is to implement government policies by providing rehabilitation programmes, services and promote the empowerment and inclusion of PWDs in society. It has adopted the Community Based Rehabilitation (CBR) approach so as to promote public awareness and empower communities to accept PWDs and integrate them in society.

The CBR programme is carried out in approximately 10 districts. The services include identifying families with PWDs and PWDs themselves, both at community and district level and supplying their needs. The Norwegian Association of the Disabled (NAD) has been supporting the programme in three districts – Blantyre, Machinga and Balaka, since 2003. The programme is well integrated in the context of the Decentralisation Act of 1998.

Policy and Legislation

A national policy paper on Equalisation of Opportunities for PWDs was ratified by Cabinet in November 2005. The aim of the policy is to:

...integrate fully PWDs in all aspects of life, thereby equalise their opportunities in order to enhance their dignity and well being, so that they have the essentials of life¹.

The key institutions that carry out the implementation of the policy are as follows:

- Ministry of Persons with Disability and the Elderly
- MACOHA
- Federation of Disability Organisations of Malawi (FEDOMA)
- National Coordinating Committee on Disability Issues and Local Government.

Malawi has drafted a Disability Act. PWDs through FEDOMA played a major role in the drafting of the Act. It is now with the Ministry of justice and will be taken to Parliament for debate and passing.

In Malawi, the President has an Advisor on disability issues. Although the political environment is not conducive for PWDs to campaign for a Parliamentary seat, one of our own is a member. He managed to get to Parliament by election just like everybody else. When the Malawi Constitution was being reviewed recently, we lobbied for special seats to be reserved for PWDs in Parliament.

Malawi has ratified and signed the following United Nations declarations that relate to PWDs:

- UN Convention on the Rights of PWDs (signed 27 October 2007).

¹National policy on equalisation of opportunities for persons with disabilities.

- Universal Declaration of Human Rights (1948) – (signed 28 September 1960).
- International Convention on Civil and Political Rights (1966) – ratified 1994.
- Convention of Elimination of all forms of Discrimination against Women (1979) – ratified 1987.
- Convention of the Rights of the Child (1989) – ratified 1991.
- African Charter on Human Peoples Rights (1981) – ratified 1989.
- World Programme of Action concerning Disabled Persons (1982)
- UN Standard Rules on the Equalisation of Opportunities for PWDs (1993)

Education in Malawi

Malawi has experienced some major changes in education over the past years. Many of these changes were necessitated by the introduction of free primary education policy in 1994. This policy led to a dramatic increase in primary school enrolments. The school enrolment has almost doubled. However, the drop-out rate in primary schools is estimated to be at 70 per cent. Therefore, majority of students never proceed to secondary school.

In a SINTEF study conducted in 2004, only 5 per cent of the PWDs questioned indicated that they had received vocational training. SINTEF is an independent research organisation based in Scandinavia. The initials mean “The Foundation for Scientific and Industrial Research’.

Special Needs Education in Malawi

In the document *Policy Investment Framework (PIF)* 2001, the Ministry of Education, Sports and Culture addressed the need to strengthen the support system of Special Needs Education (SNE). With strong political will from the government, the SNE Unit was upgraded into a Department in 2005. The upgrading of the unit was one step to implement the Policy Investment Framework and the

National Policy on the equalisation of opportunities for PWDs. The Department has employed specialist staff in different areas of disabilities such as visual impairments, hearing impairments and learning difficulties. The present Deputy Director of the SNE Department is Mr David Njaidi, who is himself visually impaired.

In a historical perspective, schools and learning environments for disabled children in Malawi were first established and taken care of by church missions. Today there is an increasing interest from the government to participate and contribute. The government is responsible for teacher training and employment. In some areas the church missions have boarding facilities to accommodate disabled children enrolled in the nearby schools. Since then a number of teachers have been trained in SNE. The government is also in the process of building structures for the special needs teachers' college. The Special Needs department has PC reading software which can be accessed by the visually impaired. The establishment of the department of SNE is major step in recognising the needs of PWDs.

The priorities of the SNE Department are as follows:

1. To draft a SNE policy paper.
2. To develop a strategic plan for the Department.
3. To include orientation on SNE and its target groups in the curriculum for teacher training from the year 2006.
4. To hold orientation workshops for in-service teachers in collaboration with CBR-committees and CBR-workers.
5. To promote accessibility to school buildings and school toilets.
6. To disseminate information through media to promote awareness in society of the abilities of the disabled with the purpose of changing negative attitudes.
7. To create a demand for SNE through information campaigns.
8. To collaborate with other stakeholders in disability issues.
9. To work in close communication with teacher training colleges of Montfort in developing good quality SNE teaching.

10. To establish a government owned SNE teacher training institute in order to increase the number of SNE teachers. Currently there are about 500 SNE teachers in public service and 50,586 pupils enrolled in primary schools.
11. To increase the supply of teaching and learning materials, and assistive devices.

SNE is carried out in primary schools using three different methods:

1. The Department has SNE teachers in designated special schools.
2. The Department has supports integrated resource centre units in mainstream schools, staffed with SNE teachers.
3. The Department has itinerant SNE teachers assisting in mainstream schools. One such teacher normally serves up to fifteen schools.

Malawi has four special schools for the deaf:

1. Mua School, Dedza.
2. Embangweni School for the deaf, Mzimba.
3. Mountain View school, Mvumbwe.
4. Malawi Total Communication School (MATOCO)

All schools for the deaf use oral teaching methods, except MATOCO which uses a combination of oral and sign language methods. There are two special schools for the blind, Chilanga School and Lulwe School.

Montfort College

Montfort College of Teacher Training and SNE Centre was founded by Catholic Brothers (Dutch missionaries) in the 1950s. With the special focus on the most vulnerable pupils, the requirement on SNE became apparent. This was the starting point of a teacher training program within SNE. On the campus there are demonstration schools called Educational Centres. The centres are designed to serve pupils

with visual impairment and blindness, hearing impaired and deafness as well as pupils with learning disabilities. In addition to this, the Montfort School plans to expand its programmes to include deaf and blind pupils. In the past, the teacher training was divided in programmes corresponding to the three categories of disability – visual, hearing and learning disability. This has changed and now students are following a combined course which integrates all the three categories. The buildings at Montfort campus are still owned by the mission. The work at the centres is funded by government and external donors.

Church's Involvement in the Welfare of PWDs

Any disability raises fundamental theological questions about creation, human nature, God's justice and the nature of sin. Attempted answers to these questions clearly show that Churches and Christians in particular differ in response when it comes to biblical explanation of disability. However, Nkhoma Synod as a church inherited deep theological convictions from the Dutch Reformed Church (DRC) Missionaries. They taught about God's love for PWDs which unfortunately is not always manifest in the Christian church.

As part of their evangelisation strategies, the DRC missionaries established a pastoral ministry around 1900 that had built-in support systems for the natives with disabilities. For example, they introduced industrial work and agriculture which involved basket weaving, making mats and cane-chairs, wood and iron work. Many PWDs benefited from these traditional and local industries. They also imported tricycles and clutches from South Africa which were given to PWDs. The DRC missionaries also conducted sensitisation training to families who lived with PWDs. The training was meant to 'remove the social evils' and discourage them from abandoning PWDs in the bush to die as was the case before.

To help those who were blind they introduced eye clinic services. These services have now developed into a fully fledged eye hospital. They also went about sensitising the community about health problems that affect the eyes. This led to establishment of schools

for the blind. Through various churches, the missionaries made a huge contribution especially provision of schools and hospitals.

Both the Roman Catholics and Presbyterians established some schools for the blind and the deaf. For example the Roman Catholic Church established Montfort College at Nguludi in Chiradzulo district. Its purpose as we have seen was to train special needs teachers who would in turn teach pupils with hearing or visual impairment in different schools. The Catholics also established Mua School for the Deaf at Mtakataka in Dedza district. The Nkhoma Synod too runs two schools for the blind – at Chilanga in Kasungu district and Malingunde in Lilongwe district.

Apart from normal hospitals, the churches also established leprosariums. For example Kochilira in Mchinji for the Nkhoma Synod and Kankao in Balaka district for the Roman Catholics. Although leprosy is no longer a problem, the Roman Catholic Church still keeps those with the diseases at Kankao. Such persons receive provisions from both the church and government for the rest of their lives. They also escape being stigmatised by society because of their physical appearance.

Demographic Data on PWDs

In 1983, Malawi had 190,000 PWDs which translates to 2.9 per cent of the total population. Of these, 93 per cent lived in rural areas. The distribution in terms of age was as follows:

Table 20.1: Distribution of PWDs in terms of age

Age range (Years)	Percentage
5-14	2.3 per cent
15-29	3 per cent
15 to 45	40 per cent
Over 46	54.7 per cent
Total	100 per cent

Source: National Statistics Office, 1987: 6-8

A recent study on living conditions among persons with activity limitations revealed that the mean prevalence rate of PWDs has gone up from 2.9 per cent in 1983 to 4.18 per cent (FEDOMA et al 2004: 56). This represents an increase of more than 30 per cent. The number of PWDs currently stands at 480,000 – 49.5 per cent are female while 50.5 per cent are males.

In terms of distribution by region, the southern region has the highest number households with PWDs at 50.4 per cent of the region's population with the central and northern region having 50.2 per cent and 43.9 per cent respectively (FEDOMA et al, 2004: 83). In terms of distribution per disability, the distribution was as follows:

Table 20.2: Distribution per disability

Type of disability (respondents)	Percentage
Physical disabilities	43 per cent
Visual impairments	23 per cent
Hearing impairments	11 per cent
Illness	43 per cent
Congenital	17 per cent
Accidents	15 per cent

Source: FEDOMA et al 2004 cited in ILO (2007: 3)

Further, regarding acquisition of disability, the statistics are as follows:

Table 20.3: Distribution per mode of acquisition.

When disability was acquired	Percentage
At birth or by the age of 10	59 per cent
Between the age of 11 and 20	11 per cent
Between 20 and 60	23 per cent
After 60 years	7 per cent
Total	100 per cent

Source: FEDOMA et al 2004 cited in ILO (2007: 3)

These statistics show that the mechanisms of early detection disability, intervention and prevention measures and inadequate. This state of affairs has greatly contributed to the high prevalence rate of disability in the country. Most PWDs continue to find it hard to access basic services such as education, health, training and employment. The main impediments are environmental, institutional, attitudinal, economic and social barriers (Malawi Government, 2006: 1-8).

History of Disability Movement

The disability movement in Malawi started in the early 1980s. The idea was born when a group of disabled friends met under a tree to discuss the challenges they faced in their day to day living. The group became organised and recruited more members.

Further growth of the movement can be traced to a regional meeting of associations of persons with physical disabilities held in Zimbabwe in 1984. Persons with physical disabilities from Malawi were invited.

After this meeting, Disabled Persons Association in Malawi (DIPAM) was formed in 1988.

It was formed as an affiliate member of the Southern Africa Federation of the Disabled (SAFOD) with a secretariat, National Executive Committee and a Board of Trustees. Thus the disability movement in Malawi grew in strength and by the mid 1990s disabled persons from every district in Malawi were represented.

However, as different disability organisations started to emerge, services became fragmented and efforts were duplicated ultimately the impact of disability movement was diluted. The situation remained like this for some time until organisations of PWDs decided to come together to discuss and identify their needs to agree on a way forward. After the deliberations, the following common needs were identified:

1. There was need for an effective platform that would give organisations of PWDs one strong voice.
2. There was need to coordinate the efforts of organisations of PWDs.
3. There was need for building capacity for the DPOs.

4. There was need to sustain disability awareness campaigns to promote positive social attitudes and behavioural change towards PWDs.

DIPAM was formed to represent people with all types of disabilities. However with time, it became apparent that organisation's agenda was monopolised by people with only physical disabilities, in terms of both leadership and activities. Within four years of its establishment, persons with other disabilities (not physical) began to mobilise themselves with the aim of forming their own representative association. In 1992, people with hearing impairments formed the Malawi National Association of the Deaf (MANAD) to advocate and lobby for their rights. It was like an avalanche had been opened. The following associations were formed in a span of six years as shown in the table below:

Table No. 20.4: Disability Organisations in Malawi.

Association	Aim/Purpose	Year
1. The Malawi Union of the Blind (MUB)	Formed by the blind.	1994
2. Association of Albinos in Malawi (TAAM)	Formed by albinos.	1995
3. Disabled Women in Development (DIWODE)	Formed by women.	1996
4. Forum for Disability Rights (FODIRI)	Formed by George Claver ² and Mussa Chiwaula to lobby for increased role of PWDs in the national development agenda.	1997
5. The Malawi Disability Sports Association	To lobby for increased participation of PWDs in sports activities.	1998
7. Parents of Disabled Children Association of Malawi (PODCAM)	Formed by parents.	1999

²Mr. Claver was later appointed to the cabinet as the first Minister for Persons with Disability.

This mushrooming of DBOs eroded the mandate and authority of DIPAM. Attempts to revive it failed. It became imperative that an umbrella body for all disability associations in Malawi had to be formed. The representatives of the seven DBOs met in March 1999 and formed the Federation of Disability Organisations in Malawi (FEDOMA), to replace DIPAM. The formation of FEDOMA was facilitated by the Danish Association of organisation of PWDs. The mission of the federation is to enhance the social welfare of PWDs and enable them assume their rightful role in society. Its purpose was to coordinate DBOs, build capacity and give PWDs a strong voice in national affairs.

However, the formation of FEDOMA did not stop the proliferation of other DBOs. The Association of the Physically Disabled in Malawi (APDM) was established in 2002 to lobby and advocate for the interests and rights of people with physical disability. The most recent is the Disabled Women and Orphans Organisation of Malawi (DWOOM) which was formed in 2006 to represent disabled women and orphans (Msowoya, 2007: 1-3).

At the moment, the disability movement is organised under the leadership of FEDOMA. As stated above, FEDOMA offers a unified voice for all DBOs through lobbying and advocacy activities towards an inclusive Malawi. It is a membership association comprising;

- Malawi Union of the Blind (MUB)
- Disabled Women in Development (DIWODE)
- Malawi National Association of the Deaf (MANAD)
- Malawi Disability Sports Association (MADISA)
- Parents of Disabled Children Association in Malawi (PODCAM)
- The Albino Association of Malawi (TAAM)
- Association of the Physically Disabled in Malawi (APDM)
- Disabled Women and Orphans Organisation of Malawi (DWOOM)³.

³See Federation of Disability Organisations in Malawi (2006). Annual Report 2006.

The Role of FEDOMA in Development

Over the years, FEDOMA has influenced or been involved in various activities and processes aimed at mainstreaming disability with various measures of success. These activities and processes include the active participation of DBOs in a study on “Living Conditions among Persons with Activity Limitations in Malawi 2003”⁴, the development of the National Policy on Equalisation of Opportunities for PWDs during which FEDOMA served as a member of the Core Team. In addition, FEDOMA chaired the process of drafting the Bill on Equalisation of Opportunities for PWDs and of reviewing the Handicapped Persons Act. Below are some of the achievements of FEDOMA:

Capacity Building

FEDOMA conducted a training session on HIV & AIDS targeting 121 local leaders which was facilitated by peer educators. The peer educators were drawn from employees of MACOHA. The employees received initial training from the Malawi Counselling Resource Organisation (MACRO). Local leaders included CBR volunteers, village heads, religious, and other leaders within the communities. They were chosen because of their influence in the communities.

The purpose of the training was to equip participants with general information and facts about HIV & AIDS. It was hoped that they would in turn spread the knowledge to PWDs in their communities so that they can make informed choices about their sexual behaviour. More importantly, the training was intended to enable community leaders to mobilise their people to formulate and implement HIV & AIDS strategies that would help curb the scourge. On average there were 30 participants from each of the four affected districts. It was pleasing to note their involvement in the project because they serve to encourage more PWDs to join disability clubs.

⁴Over 50% of the enumerators and study supervisors comprised PWDs

In another training session, a total of 34 Community Rehabilitation Workers (CRWs) were trained on HIV & AIDS management. These workers were also targeted for training because of their constant contact and influence in the communities.

Another training session was conducted targeting 20 peer educators in order to realise a multiplier effect in the disability sector and in the communities

The other training session in sign language was conducted for 21 participants drawn from government hospitals and nongovernmental organisations. The main targets were those involved in HIV & AIDS activities such as Development Aid from People to People (DAPP), Tovwirane Centre, MACRO and MACOHA. All of them are located in the four affected districts. The aim was to equip them with knowledge and skills in sign language interpretation so that they can effectively assist persons with speech and hearing impairment in their work places.

Advocacy for Accessible Physical Environment

FEDOMA as an advocacy organisation has been working with relevant stakeholders to promote inclusion of PWDs in development activities. Several community awareness campaigns were conducted to sensitise the general public, policy makers and service providers on the need to make buildings accessible to PWDs.

FEDOMA also held discussions with the Office of the President and Cabinet on the need to make all government buildings accessible. It proposed adaptation of old buildings and ensuring that new ones are disability friendly. The Office of the President and Cabinet agreed and the process is underway. A circular to that effect has been issued to the relevant department to ensure that all buildings are disability friendly.

Youth with disabilities were trained in advocacy skills so that they further advance the advocacy programme already established in their respective districts. Many have organised themselves and represent PWDs in other community development committees. Civil

society organisations were also sensitised on disability issues through a workshop arranged by FEDOMA.

Access to Information Communication Technology

Most public information is available in formats that PWDs cannot access. FEDOMA, in an effort to reverse this situation has held meetings with providers of such information with a view of persuading them to cater for persons with various disabilities. In conjunction with MACOHA, FEDOMA produces materials in Braille which they use as an advocacy tool when sensitising various service providers.

MANAD has also been involved in training lecturers and other service providers in basic sign language. This has helped lessen the communication barrier between persons with hearing and speech impairments and the community. Currently they are in the process of producing a sign language dictionary. Through awareness campaigns, the media has also been sensitised on the need to include sign language and where possible use large print and or Braille. MACOHA produced a television programme with a sign language insert to sensitise policy makers and the public at large on sign language. FEDOMA teamed up with a famous local musician to produce a music video highlighting disability as a human rights issue. The video also includes a sign language interpreter translating the lyrics of the song.

Inclusive Education

Through the influence of FEDOMA, the government established SNE to ensure that children with disabilities also attend regular classes. FEDOMA has also been involved in sensitising parents of children with disabilities to send them to regular schools where possible. According to statistics, 34 per cent of PWDs have never been to school⁵. To encourage PWDS to enrol for school, FEDOMA assists needy students to pursue education even in regular schools.

⁵2004 Living Conditions of People with Activity Limitation research conducted by Centre for Social Research and FEDOMA.

It also lobbies organisations or partners to pay school fees and buy school materials for them.

Learning Materials for the Blind

Learning materials for blind students are available in very few mission schools. Many government schools do not provide materials for blind students. With the establishment of SNE, it is hoped that the government will available such materials soon. As a gesture of commitment, the concerned government Department purchased one embosser for administration purposes.

Inclusive Vocational Training

FEDOMA works closely with MACOHA – the agency implementing government disability programmes. MACOHA runs the CBR programme and has several vocational training schools in the country where many PWDs are trained. These vocational training centres are open for both PWDs and those without. FEDOMA is also working with other training institutions like government technical colleges. It has successfully lobbied for the renovation of colleges that enrol more students with disabilities so that they can cater for their needs.

Access to Job Market

FEDOMA in conjunction with the Ministry for Persons with Disability made joint efforts in sensitising policy makers on the need to employ PWDs. The Office of the President commissioned the Ministry to solicit Curriculum Vitae of PWDs and submit them to the Department of Human Resources for possible employment in the civil service.

Accessible to the Workplace

Many places of work in Malawi are not accessible to PWDs. The main problems are twofold: inappropriate physical infrastructure and the attitude of employers themselves. FEDOMA through its radio sensitisation programme reminds employers to also consider PWDs

when recruiting. This is likely to improve after the implementation of the disability policy which has been approved by cabinet.

Environment

FEDOMA is a member of the Council for Non-governmental Organisations in Malawi. The Council has member organisations that also deal with development activities. Through meetings, FEDOMA is able to sensitise them on the need to cater for PWDs. Currently some disability community based organisations have benefited from the government by carrying out development programmes in their communities. FEDOMA's collaboration with MACOHA has also enabled PWDs in the districts to benefit from the CBR Programmes. Some banks and schools have been renovated to make it easy for persons with physical disabilities to access them.

Poverty Alleviation

FEDOMA is aware that PWDs are the poorest of the poor in Malawi due to disability and an inaccessible environment. To help uplift their lot, the government established a rural development fund (MARDEF) to support local business initiatives. The disability movement is represented in the management board of this fund. Some groups of PWDs have received funding from this programme. It is hoped that MARDEF will go a long way in alleviating poverty among PWDs especially those in rural areas who make up 90 per cent of the population. Other development funding initiatives by the government that support disability activities in the communities include the Malawi Social Action Fund. This programme is run in phases. Now in its third phase, it is giving support to community development activities like building. Initiatives of some disability community based organisations are supported by such programmes and are doing very well at grassroots level.

Gender

Malawi has a Gender Policy formulated by the Ministry of Gender and Community Services. An awareness campaign targeting gender balance is ongoing. All Institutions, organisations and companies are alive to this policy and are gender sensitive in their programmes. Partners and donors have put a condition that all programmes they support are not gender biased. The disability movement has not been spared, and FEDOMA in particular trained women on gender because men dominated all disability organisations. The training was based on the need for women to participate fully and contribute to the development of the disability movement. FEDOMA has a representative in the Gender Network, a network of civil society organisations that promote gender issues in the country.

Education

The federation works in collaboration with the Ministry of Education, especially the special needs department. FEDOMA is involved in the production of educational toolkits and development of the curriculum for the special needs teachers.

Human Rights

FEDOMA is a member of the Human Rights Consultative Committee (HRCC). This committee is comprised of about sixty-seven (67) human rights organisations. It was set up to promote and protect human rights through advocacy, information sharing, capacity building and resource mobilisation for member organisations. It fulfils its mandate through coordination with state institutions, government and key stakeholders. HRCC has instituted a disability and the elderly directorate in its operations. It supported FEDOMA to organise constitutional awareness campaigns in two districts in the country. PWDs participated fully in these meetings by attending in large numbers and responding to issues raised during the meetings. PWDs are also represented in the Malawi Human Rights Commission, an independent institution concerned with the promotion, protection, and

enhancement of all internationally recognised human rights in all facets of Malawi society.

HIV & AIDS

From 2003 to date, FEDOMA has been implementing a project on effective HIV & AIDS and reproductive health information for PWDs. The project is supported by the Canadian International Development Agency (CIDA). It aims at ensuring that issues that affect men and women with disabilities are included in the national HIV & AIDS policy. It champions equal access to information and active participation of PWDs in HIV & AIDS awareness and initiating programmes. The project involved conducting a research on the impact of HIV & AIDS on PWDs.

Findings indicated that persons with hearing and speech impairment are the most vulnerable because of lack of information on the pandemic. The results also show that most PWDs get information on HIV & AIDS through radio. Under this project, women were trained to be peer educators and eventually become HIV & AIDS desk officers in their disability organisations. After the training, the women organised other workshops with disability stakeholders to review the national HIV & AIDS policy. The results of the workshop reviews were unanimous that disability issues were not clearly articulated in the policy. The women resolved to meet the policy makers and share their concerns.

Another workshop was also organised for the HIV & AIDS stakeholders to sensitise them on the need to include PWDs in their programmes through demonstrations. Many stakeholders pledged to start including PWDs and also seek advice from the federation on disability issues from time to time.

In the same project, trained women organised community awareness campaigns on the need to include PWDs in the community HIV & AIDS programmes and initiatives. The campaign activities included demonstrations on the streets with people carrying messages on inclusion of PWDs, reciting poems and drama, performed by PWDs and the community at large.

FEDOMA sponsors radio programmes to sensitise PWDs on the available HIV & AIDS services and generally acquaint policy makers about the need to include PWDs in HIV & AIDS programmes. FEDOMA, through the partnership with CIDA is often invited to their partnership meetings to give presentations on disability and HIV & AIDS. It uses this platform to advocate for mainstreaming disability in HIV & AIDS programmes.

Personal Experience

I was born in a village, in a family of eight children, four boys and four girls. At the age of three I got sick and later it was discovered that it was polio. Every part of my body seemed dead except the heart which was still beating. People started mocking my mother and telling her to bury me since I was dead, but my mother refused.

In time I started coming up. I started crawling, and later walking using a stick. Soon after my father got a job with a radio broadcasting station, so we moved to the city. I started school late. Generally I was a shy girl. I always felt inferior. I used to question God as to why He created me as I am.

As years went by, I discovered that I am unique before God. We see Paul pray three times to God to remove the thorn in the flesh (2 Cor 12:9). Since the bible does not explicitly state what this 'thorn' is, many people associate it with some kind of disability. But God did not do that. Instead, He said, *"My grace is sufficient for you, for my power is made perfect in weakness"*. Thus God accepts someone whatever the condition for the sake of His glory. I am always proud of myself because I am a unique person, different from others. The glory of God is always manifested in me.

I have many testimonies to tell of how God has seen me this far. I always give an example of a flower garden, to say if you have one type of flower in that garden, it does not look beautiful. But, if there are different kinds like red, white and yellow, it looks marvellous. So I am a white flower in the garden of red roses! It is good to accept what God has given us and shun bitterness in life. This is very important because some people think all PWDs need healing.

Many preachers these days call all PWDs for healing, as if we are not supposed to be disabled.

Challenges Faced by PWDs

PWDs face three major challenges: First, society still has the negative mindset that a PWD cannot have relationship, marry and have a family. Such is the notion, especially when it comes to PWDs who are woman no matter how educated and cultured the people are. Society seems to be baffled – after all how can they manage?

Second, several injustices are meted to PWDs. There are cases where some women and girls with disabilities are raped, abused and have their rights violated. The cause is the primitive beliefs and negative attitudes of society, which leads us to the third factor, perception.

Women with disabilities are not perceived as women but rather as disabled. Women and girls with disabilities should demand respect, be visible and take time to participate in societal activities.

Two factors are responsible for exclusion and violation of the disability rights: ignorance and negative attitude. PWDs have a right to form and enter into relationships and family life as stipulated in the UN Convention on the Rights of PWDs (Article 23).

The Issues

From the discussions, three major issues stand out, as summarised below:

Negative Attitude

Negative attitude towards disability has been with humankind since the time of creation. God created man in God's own image. This image was conceived to be that of a perfect human being. However, ever since the very same man began to experience various disabilities, the society began to despise him. Until today, very little has changed in terms of the society's perception of disability. Even in this modern day PWDs are denied opportunities on the grounds of disability.

Sexuality, Family and Children

Women with disabilities are denied marriage and parenthood. A man who marries a woman with disability is assumed to be desperate. Family members resist and dissuade the man, falsely believing that such a marriage would bring bad luck. At times, when such couples are denied holy matrimony, the result is short term or often abusive sexual encounters with whoever comes their way.

Such was my story when my husband proposed to me. People were curious and irritating by their line of questioning! "Why does such handsome man want to marry this one?" they would ask. That split the family: those for and those against.

At my place of work, people would beckon each other every time he came to visit me. "Come and see the man who has proposed to a disabled woman." They would whisper to each other. "He should not have proposed to you!" the few brazen ones would tell me face to face. Society assumes that PWDs cannot fall in love, let alone get married. This loneliness could be one of the causes of death among PWDs.

I know of a real life story of an abusive relationship involving a PWD which led to divorce. There was this woman who had an accident, resulting in permanent disability. She was hospitalised for eight months. When doctors decided that she should have an amputation, the husband refused to sign the papers. He feared that the woman he loved would no longer function well as woman. By good luck, her parents signed the papers to authorise the amputation.

After being discharged from hospital, she returned to her matrimonial home. However, the husband's behaviour became strange: he at times failed to come home. The woman was frustrated and through perseverance, spent several sleepless nights.

The woman started participating in the disability activities. This gave her confidence about her new life and condition. The husband was not happy with this development. He became so jealous and threw her out of their matrimonial home. Asked why he was doing this, he replied that she was no longer a proper woman. She left the home with her two young daughters and started living as a single

parent. Through hard work, her situation improved. She became economically empowered and bought a house. When the husband came to know, he again wanted her back home, but she has refused.

Another concern is, a child with disability can be a cause of divorce in the home. Most often, the blame goes to the woman. The husband may even leave. Even if families stick together, the attitude is always there. Once, I met a family which, when asked the number of children they had, stated that they have 'five children and the sixth is disabled'. This was a shock to me. This response speaks volumes about disabled children.

In traditional African societies, a woman is judged by her ability to bear and care for children including their father. It is unfortunate that even when disabled women bear children, they are sometimes seen as incapable caring for them. Another true story is told of a couple who were deaf. They were blessed with two children, but the relatives took the kids for fear that they will become deaf.

Still with tradition and culture, many household chores are done by the woman – drawing water from the well, fetching firewood, cooking and tilling the land. The negative attitudes towards disabled women arise from the feeling that they cannot perform these duties, hence – need not have a family.

When a disabled girl child reaches puberty stage, she is not trained or prepared for motherhood. It is thought that she is not marriageable. The start of the menstruation period is a concern to the mother. Families opt to sterilise such girls so as to avoid the embarrassment of being impregnated or going through menstruation periods.

UN Convention on the Rights of PWDs

The issues discussed above are all violation of human rights. The Human Rights charter of 1948 has not ensured equality. A section of people have been denied these rights, hence the UN Convention on the rights of PWDs. Questions may arise as to why the specific convention? The idea is to address the 'invisibility' issues. As Quinn and Degener have noted, PWDs have been effectively "Invisible"

within the UN Human Rights System. Other groups (such as women and children) experienced this same kind of “Invisibility” in the past, and they too opted to develop “Thematic Human Rights Conventions.” These we know as the Convention on the Rights of the Child (CRC), and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

Likewise, the World Health Organisation estimates that there are 650 million PWDs all over the world: I would say therefore that there are:

- 650 million PWDs all over the world who are made invisible by external environments
- 650 million PWDs who are a forgotten group when it comes to the enjoyment of civil and political rights, and,
- 650 million PWDs who are the last to be considered in the many areas of economic, social and cultural policy development and legislative reform

Testimonies of Negative Attitude

Let me share two experiences from my many travels. In the first experience, I was travelling to one of the countries in the Southern African region on one of the SAFOD programmes. On arrival, in Johannesburg I went through the normal security check at the in counter. In the process, a lady security officer sought to know the cause of my condition. I genuinely informed her that I was struck with polio. Nothing had prepared me for what followed. She then asked me “Why?” and continued “Why you?” In response, I asked her “If not me, who should it have been?” She was dumbfounded. I just laughed and moved on.

In the second incident, I was on my way from Cape Town. There was this gentleman who was assisting me to push the wheelchair. Suddenly, he asked me why I was in a wheelchair. I gave him the same answer. His retort was somehow baffling, “Maybe you did not pray enough!”, he said. What an attitude!

To cap up this section, I will tell you the story of my friend. For this purpose, let us call him Abisai. Abisai is visually impaired. While in a certain tertiary institution, there was a revival meeting at the campus on one of the weekends. Fellow students made arrangements with the pastor to pray for him. Their intentions were good; they wanted their friend to be healed. When the time came, nothing happened despite their numerous prayers. They kept on pleading with him to have faith in God so that he may receive his healing. Still, nothing happened. Eventually they left him. Because of this incident, Abisai started backsliding. But because God's grace is sufficient and surpasses all understanding, Abisai came back to the Lord, and now he is a pastor of his own church in Lilongwe.

Conclusion

The plight of PWDs does not get the attention it deserves, not because of God's arrangement but because of the church leadership. Although, the church was commissioned to fulfil the mission of the Triune God, it has not been true to its calling. From the analysis, in this chapter, it is obvious that the church is not doing enough to assist PWDs.

Information in forms accessible to PWDs is very scarce. The church should work out programmes that can prepare PWDs to participate fully in the church. Showing concern for PWDs is a fulfilment of God's command. Two ways of showing concern come to mind. First, the church should supplement government efforts in offering technical skills to PWDs and intensify the same. Second, through advocacy, the church can raise awareness about the plight of PWDs to the general public and congregations in particular. The church needs to be on the forefront on matters that affect PWDs since they are issues of social concern. The church has to strongly speak out against any social injustice affecting PWDs since it is better-placed to do so. The congregation on its part needs to accept PWDs so that we can worship together and also respond positively to the needy. We need to stop talking and swing into action.

The Church as an institution has always been a pioneer in many ways, as seen in education in Malawi. It would be therefore prudent if the Church can champion issues that affect PWDs. Only then will other actors in society become serious and give them equal opportunities and treat them fairly

CHAPTER TWENTY ONE

A Profile of Tanzanians with Disabilities

Kaganzi Rutachwamagyo

Overview

Tanzania has over 120 ethnic communities all with diverse values, beliefs and cultures. This Chapter profiles persons with disabilities (PWDs) in Tanzania from a traditional, cultural and policy dimensions. Factors that cause disability are discussed against the background of international perspectives, norms and standards.

Although, there is no agreement on the definition of ‘disability’, many disability scholars and activists concur that the main aspect of concern is social exclusion. This includes deliberate or unintended denial of opportunities to PWDs and violation of their human rights.

Traditional Beliefs about PWDs

Mbiti (1995) argues that “birth and childhood are significant perpetual social processes which start long before a child is born. A ‘birth’ is significant because children are the buds of society. Each birth marks the arrival of spring when life shoots out and the community thrives. As a bud of both the immediate family and the community at large, a child has a communal obligation to society. Its lifelong mission is it to replace those who die and take over communal roles, duties and functions from those who are aging. The main goal is to ensure continuity of the family lineage.

However, the birth of a child with impairment is viewed with suspicion. We have already noted that such an occurrence is associated with wrongs committed. The same applies even in cases where one becomes impaired later in life. Kisanji (1995) correctly points out that the blame for 'wrong doing' is normally put on one spouse, usually the woman. When disability is associated with superstition, it leads to stigmatisation of those affected together with their families.

Mbiti's contention above means a child is supposed to contribute socially and economically to the well being of the family. Unfortunately, this expectation wanes once impairment is noticed in a child. The birth of such a child is seen as a bad omen. Deriving mainly from ignorance, the community thinks of such a child as a source of stigma and lifelong liability. This perception leads to and has resulted in desperate coping methods as discussed below.

In some parts of Tanzania, many people are ambivalent about the question of disability. Some people believe that PWDs are super human, wield extra-natural mystical powers that can either harm or benefit the community. Therefore, the how PWDs are treated depends on the perception of the family.

In addition, the language used expresses society's despondency following the birth of a child with disabilities. It is regarded as neither being an asset nor an equal member of society. So are the beliefs and attitudes of most members of the community.

In this respect, PWDs in Tanzania are generally looked upon or portrayed as defective, infirm, invalid, unable, unfit and freakish. The legacy from the past lingers on to date. As argued elsewhere in this book, derogatory terminologies and labelling are common in communities. Unfortunately even Holy Books, preachers as well as medical professionals tend to promote the use of words like *vipofu* (blind); *vivete* (crippled); *mabubu* (the dumb).

Many preachers nowadays emphasise the faith healing concept to their followers. Unfortunately, this only reinforces misconceptions, the negative attitude and self-rejection among followers with disabilities.

Coping Methods among Traditional Communities

Infanticide

Infanticide is the crime of killing a young child. Even in very recent times, Tanzania has witnessed such incidences of children with disabilities being killed by their parents particularly in the Maasailand. In the case of pastoralists, such resentful incidences are premised on community livelihood which is livestock keeping. Children with disabilities are killed with the excuse that such children cannot endure long treks in search of pastures especially in the dry season.

In the coastal region, the story is the same. After attending to a woman in labour, it is the traditional birth attendant who breaks the news. Reporting that *Mtoto si riziki, bahati mbaya* (child is not a blessing, bad luck) means the born baby has been suffocated outright – on noting signs of severe impairments. Apparently, this practice has been around for some time.

Perhaps infanticide is responsible for recent spate of attacks and killings targeting albinos. Statistics show that between November 2007 and May 2008 about twenty five murder cases of people with albinism (old and young) were reported. All of them were murdered in cold blood with the attackers escaping with excised body organs. Rumour has it that greed for wealth is behind such barbaric actions. The culprits believe that albinos are superhuman with powers that can attract wealth particularly in prospecting minerals and, fishing.

This believes and consequent actions confirm Mbiti's assertion that:

African religion has no definition because it is limitless. Traditional religions permeate all areas of life with no formal distinction between the sacred and the circular, the religious and non-religious, the spiritual and the material. Africans, who are notoriously religious, carry their religion wherever they go. Religion is carried to the fields to grow seeds or harvest new crops; to the beer party or to attend funeral ceremony; those engaged in

education take religion to the examination rooms at school or university; politicians take it to parliament.

This argument may sound anachronistic but – ongoing unprecedented events in Tanzania support it. Can you imagine twenty five Tanzanians with albinism being killed in cold blood within one year only? In this contemporary age – where science and technology are abundant?

Abandonment

The second form of coping with children with disabilities is abandonment – a practice that is considered ‘lenient’ when compared to killing. Two main reasons advanced for this practice are: keeping away ‘the curse’ and stigma. Children with disabilities are abandoned on grounds of stigma, especially at the instigation of the male spouse.

Two cases come to mind, first at the district where I provide rehabilitation services to children with disabilities. Second, similar cases are reported to police by almost every residential institution, be it a school or a care centre. For example, in a sideline project I manage, 86% of beneficiaries of the rehabilitation services are cared for by single mothers. Also, a Social Welfare Department report reveals that most of the matrimonial cases dealt with in the last three years relate to desertion and divorce. All these cases of abandonment are based on disability grounds.

One of the causes of abandonment is the breakdown in the social structure that regarded the child as belonging to the community. Since the traditional safety net has been removed by urbanisation and individualism, it has become a personal problem. Most often, desperate mothers abandon children with severe impairments mainly due to mainly economic hardships. Here, they hope that the children will escape fate by falling in the hands of good Samaritans.

Unfortunately, most of these children end up in homes, leaving squalid lives or losing their lives all the same. Only a few may be lucky. The numbers of well wishers are dwindling while that of the needy is on the rise. With social services on the decline and prevalence of poverty and HIV & AIDS many girls find themselves under

pressure to abandon their loved ones. Some after being deceived by men – never want to bear the ‘burden’ of bringing up children alone.

Overprotecting the Child

The last form of coping is through overprotecting the child. This is a situation where families revere and treasure members with disabilities, hence keep them in confinement. Legends from Hebrew, Hindu and even sedentary African communities reveal that, people with disabilities were thought of differently. Two schools of thought emerge, first is the one that considers PWDs as holy, mediums with god, unique and special.

The second school of thought considered PWDs as too feeble to do anything on their own. It was thought that PWDs were manifestations of gods’ wrath which warranted their being secluded and provided for in order to appease the spiritual world.

Ironically, research findings show that today, many families – and particularly the rich, confine family members with disabilities in their houses mainly because of stigma. In contrast, poor families tend to overprotect members with disabilities out of true love, fondness and unwavering hope. Stories abound where mothers have risked their own lives for the sake of their defenceless children who are PWDs. When the mother parts with her disabled child for any reason, her face tells it all. In most folklore, a woman who gave birth to a gimcrack pleaded for it to be spared on grounds that it came from her own womb. Since then, society was mainly patriarchal – women had to plead their case before men.

My life experience confirms the above accounts. Idd Amin Dada attacked Tanzania in 1971 when I was in a boarding secondary school. Security measures were taken including digging trenches and practising to use – just in case of air raids.

As the situation worsened, many institutions including schools were ordered closed. Unfortunately, there were no organised evacuation plans. Immobile as I have been for decades, I had to remain in school. My mother had always been worried about my safety away from home. When she came to know about my

predicament, she and her two close friends could not bear it. They walked for miles and miles on bare foot to rescue me.

When they at last found me, their feet were already soared. Worse still, I was too heavy to be carried by the now old and ageing women. We all cried for hours – but at last we had to part. I was left behind all the same so that they can organise how I could be rescued. Obviously, these brave women were driven by immense love over me.

Some parents or teachers give nicknames *fyatu* or *mwezi mchanga* to children with intellectual disabilities. Such nicknames denote lunacy.

Current Status and Effect of Cultural Traditions

As a result of the perceptions and retrogressive practices, PWDs face serious threats from abject poverty, ignorance, disease, oppression and powerlessness. They have no access to social services and are not involved in day to day social life. Thus, many do not ultimately realise their full potential. This section will discuss how PWDs are affected and their issues under different headings. But first, what is anthropology?

Edward Taylor defines anthropology as cultural segment embedding the whole complexity including knowledge, beliefs, art, morals, laws, customs and artefacts acquired mass as members of society. Abraham (1966) perceives culture from the social perspective as “...ways by which the interaction of people is affected. It is a basis on which social structures manifest, rest, grow, develop, progress, stagnate or retrogress.”

Long time ago, culture was pivoted by a consanguine family. Any signs of tension, frustration or rebellion addressed immediately to achieve harmony and peace. A part from isolated and extreme cases, PWDs benefited much from the consanguine type of family setting. The most common beneficiaries were those with mobility and sight impairments because they were mainly consigned at home. They acquired a lot of indigenous knowledge passed to them by elders through riddles, folklore, rituals and narrations on dispute

settling processes. This knowledge made them not only resourceful in their communities but also buoyed their ego, elevated their social status and won them friendships.

I personally benefited a lot from this traditional social setting. At school I was nick named a *centurian* because of being immensely knowledgeable on traditional ways of life. Even now, many salute me as *Mzee* or *Babu* for the same reason. Although PWDs in the present generation are unique in their own way, in a way they have not benefitted much from societal changes. To an extent, they have been victims of urbanisation, limitations of formal education and changes in traditional settings. The effects of these changes are discussed below.

Education

The formal education system is not inclusive. Only few PWDs access education mainly in a segregated setting – detached from the traditional fountain of wisdom. The eroding of the consanguine family has equally created a vacuum. It divests PWDs from the traditional safety net. They are thus compelled to migrate to urban centres where they unfortunately end up leading brutish and nasty lives in emptiness. The National Census Report (2002) reveals that only 0.4% of PWDs had reliable income through dignified employment.

Disability rights activists correctly point out that PWDs are viewed as victims of impairment. As beneficiaries of charity, alms and trivial services – Harris et al (2003) states that it is as if society expects PWDs to be grateful. This notion is based on the philanthropic or charity model as argued elsewhere. Unfortunately, this approach still lingers on to date.

Basic needs and social services for PWDs are provided by Faith Based Institutions, individuals and the private sector. The government on its part has offered an insignificant and unpredictable social support system. It is only in the last three years when a little improvement in this regard has started to register. However, too little has come too late and in a disempowering form. The National Strategy for Growth and Poverty Reduction places PWDs under the “improved

quality of life and social well being cluster”. This in a way confirms how the government views PWDs – recipients of charity. The growth and good governance clusters geared towards empowering citizens, do sideline citizens with disabilities. Instead, they will be covered under what is known as the Social Protection Framework if at all it will materialize.

Dependency

Most PWDs have become totally dependent on well-wishers who in turn gain gratification from the practice. Charity is basically provided at the discretion of the giver, often on the basis of ‘worthiness’. According to Harris et al (2003) PWDs who ask for more support or question the status quo are quickly labelled ungrateful – a situation that can most likely lead to withdrawal of support.

A good number of PWDs are compelled to change religion as a condition of getting relief support. In so doing, their dignity, independence, quest and will power are compromised. These kind of happenings infringe on the other civil and social rights.

Coupling

In Tanzania, it has become a norm to find couples among PWDs have the same impairments. This is because; it is hard for non-disabled persons to agree to matrimony. Thus, commonality of predicaments becomes a binding force. However, women with disabilities are the most disadvantaged when it comes to marriage. The idea of being unable to find a partner exposes them to continuous sexual abuses, unplanned pregnancies, forced abortions and the high risk of contracting HIV & AIDS.

Ostracism is warranted in the event of a non-disabled family member marrying a PWD. The following vignette supports this observation.

Victor Katumbi is physically impaired and a pious member of the Free Pentecostal Church of Tanzania. A month ago, he asked a girl in the same church for her hand in marriage. The girl was

from an equally pious family. Victor worked for a rehabilitation centre that belongs to the same church. Indeed his fiancée's brother (Frank) used to be Victor's boss at this centre.

A year ago, the Church had resolved to and indeed drafted its own policy on disability. The policy will be launched mid this year.

When information about the betrothal reached the girl's family, the idea was rebuffed with unrivalled bitterness championed by Frank – the girl's brother and Victor's former boss. When the two families failed to agree, the matter was referred to the church. Surprisingly, the church that purports to care about PWDs, sided with the girl's family. It failed to agree to bless his marriage.

Out of desperation, Victor notified the church that he had opted to take his marriage vows at the District Commissioner's office. This shocked the church. In retaliation, the church threatened Victor with a sacking if he went ahead.

However, the church later somehow softened its stance and asked him to visit the girl's parish located hundreds of kilometres away to resolve the matter. This he did, but at his own peril. He fell sick on arrival and for the first time in his life diagnosed with hypertension and asthma. He died some hours later. Although the girl's family seemed to resent the outcome of its position, an irreversible damage had already been done.

DPOs and Collective Bargaining

Abraham's definition of culture shows that its influence on the effectiveness of civil organisations is obvious. It is always easy to advocate ideas that are compatible with community values and attitude. On the contrary, advocating ideas that are incompatible with societal thinking is an uphill – if not outright disappointment.

History

Collective struggles by PWDs to participate in public affairs started modestly in 1964. These were influenced by international developments where blind people were coming together to deliberate on their plight. The struggles were motivated by the fact that, as early as 1950, special education for the blind had already been introduced. This brought students of similar disability together. By

the 1970s people with physical disabilities had also started organising themselves somehow.

After the International Year for Disabled Persons (1981), a number of other single-disability organisations came into being. These included DPOs for deaf people, parents and guardians of people with intellectual disabilities and those with albinism and very much recently those with deaf/blindness.

To date, there are around six membership based national organisations under the auspices of the Federation. Also, several professional service-oriented or pro-disability institutions were formed simultaneously. Despite having missions with a political tone, their accomplishments have been very marginal. The reason for little success can be attributed to the laxity during the socialism era which formed a fragile foundation for these organisations. Thus, Tanzanians have to build on when it comes to wooing opinion through rigorous advocacy.

It seems as if global and domestic changes – whether friendly or adverse – got PWDs unawares because they lack unity, bargaining power and the ability to exploit opportunities in their environment and optimally. It would be good if PWDs understood the saying that “change comes from power and power comes from organising.”

Institutionalisation

Apart from special schools which are characterised as a form of institutionalisation, there are no significant welfare oriented institutions. Persons with different forms of disability from diverse backgrounds join single disability organisations. The reason, the Economic and Social Commission for Asia and Pacific notes is:

...it is usually not feasible to establish organisations of persons with a single disability in a village or small town, simply because there are not enough persons with one disability.

In the Tanzanian, single-disability organisations are somehow active at central level and in some major towns. Needless to say,

institutionalisation is deep rooted in other countries including Zimbabwe and Lesotho.

Management

Decision-making processes in these DPOs – to some extent – involve members through representation and self-advocacy at national and regional levels. However, majority have so far not clearly understood their role. They are also not accorded the chance to participate in the day-to-day running of their respective organisations. This prevailing situation has in a way contributed to inability to achieve the set goals. Since single disability-organisations are run on voluntary basis. Thus, the advice by Mandela (1995) that “Judge an organisation by the people who belong to it – whether they are truly a unity or a mere collection of individuals” rings true.

Advocacy

Organised advocacy is non-existent among Tanzanians with disabilities. We still have a long way to go to realise destined civic and political rights. Here, even issues that are regarded as ‘mainstream’ require extra effort from civil society to get the government to act. Two factors are responsible: first, governments all over the world are populists – they adopt many policies to please the majority. Second, bureaucrats and policy makers gladly ignore issues raised by flickering voices. They oversee enactment and enforcement of legislations that are unfavourable to PWDs. Hardly do they even attempt to consult them. The dictum by Freire (1968) that “oppressive acts capitalise on the minds of the oppressed” could as well be true. Instead of yearning and collectively striving for transformation, PWDs remain indifferent to their own plight.

To promote advocacy, PWDs have to undergo sincere self-critique and soul searching so as to determine the way forward. They have to overcome psychological oppression, inferiority complex and self-centredness. With the numbers and leadership from the elite among them, they should be bold enough to challenge the status quo.

Unfortunately, most of the PWDs in Tanzania who are educated are averse to DPOs and tend to distance themselves from advocating disability issues. This has created a divide where not all PWDs speak with one voice. This goes against the spirit of the founders of the disability movement:

...let us reason together, let us deliberate on our problems and needs, let us consider our abilities, and when we have agreed on the problems and solutions, let us articulate our opinions and ideas in a strong and united voice. (Derksen, 1975).

Hope lies in a gradual evolution through self-exploration and understanding – where persons with disabilities became emancipated to the level of choosing how they should be described, named and treated. When this time comes, terms such as ‘impairment’ and ‘disability’ will be redefined and made distinct from the common anachronistic labelling.

Disability from the Policy Perspective

Once, Mwalimu Julius Kambarage Nyerere quipped: ‘Is water immediately drawn from the well different from that remaining behind?’ The correct answer is that though in different containers – in this case – the water remains the same. This quip is related to how attitudes surpass individual and community boundaries to higher levels of decision making. In making decisions, some decision makers stereotype PWDs – as discussed – just like the communities they come from. Quite often, most policies, legislations, programmes and budgets sideline or are insensitive to PWDs.

International norms and standards notwithstanding, policies on education, infrastructure, health, communication, employment, good governance, etc. infringe on the rights of persons with disabilities. The church has not been spared either – whether it is through mistakes of commissions or omission. These are categorised as institutional barriers and are discussed as follows.

Access to Buildings

As pointed out elsewhere – access to buildings by PWDs is a major challenge. Buildings that provide services to the public like banks, post offices, churches and mosques lack basic facilities like lifts or ramps. The same is the situation for markets, airports, public transport system, stadiums and other infrastructure.

Access to Education

Access to both formal and informal education is very limited for PWDs. Although there have been recent moves to expand basic education, no attention has been given to special educational needs. For example in 2007 – according to Save the Children Fund-Tanzania there were 1.7 million children below 18 years of age who should be in primary school. However, the Poverty and Human Development Report (2007) reveals that only 24,003 or 1.4% of school age children with disabilities are enrolled in primary schools. This is an increase of only 0.3% from the preceding year. This is very disappointing. Other disappointing factors are as follows:

- (a) Both the pertinent legislation of 1978 and the current Education and Training Policy (1995) are silent about persons with disabilities.
- (b) A survey conducted by Information Centre on Disability (2008) reveals that in the last three years, the average school drop-out rate among pupils with disabilities stands at 39.75%.
- (c) The number of special primary schools (including units) does not exceed 185, while under the Primary Education Development Programme, the number of conventional primary schools stood at 15,624 (both public and private) in 2007. This means schools catering for children with disabilities constitute only 1.19% of all primary schools in the country.
- (d) The question of inclusive education remains unaddressed.
- (e) The issue of quality education for the few who make it to formal education remains questionable.

- (f) The number of children with disabilities enrolled in primary schools is decimal compared to that of neighbouring Uganda and Kenya.
- (g) The picture is gloomier when it comes to transitional measures after primary education – access to secondary school or tertiary education remains a nightmare.

Access to Health

Many PWDs require basic medical services like consultation, drugs and other therapeutics including those related to rehabilitation. This is not the case in Tanzania. The Health Policy of 1991 is quite silent about PWDs. Some groups of people are automatically exempted from paying for health services. These include children below five years, the elderly, pregnant women, those infected with HIV & AIDS and Tuberculosis. However, the government has been very reluctant to accord persons with disabilities similar automatic exemption. To be exempted, PWDs have to apply, be assessed by different authorities regardless of how seriousness their disease is – quite a cumbersome process. Similarly, for those who require technical appliances – costs are rather prohibitive while – availability is also a problem. As such philanthropy remains the only handy option.

Dependency Syndrome

With the introduction of Structural Adjustment Programmes – many free social services targeting PWDs in Tanzania were withdrawn. Those who were living in institutions and vocational training centres suffered most due to lack of basic social support. Some of the social facilities closed down to date.

At this time, begging on streets reached its zenith and has never declined – perhaps a gratifying opportunity to those who give alms to gain publicity. Many corporate bodies including the White House have made it a ritual to donate foodstuff to the needy on the eve of religious celebrations like Christmas, Eid al-Fitr and Easter. One tycoon throws generous luncheons to thousands of PWDs every year

in presence of top officials. Even the government seems to be encouraging its departments and other rich people and to emulate this practice. Surprisingly, leaders of DPOs do attend and savour such meals with no qualms about the implication. Measure

Proponents of charity for PWDs in Tanzania could learn from the Chinese dictum that says:

Give someone a fish – you are feeding him/her for a day, but by teaching someone how to fish and giving him/her fishing nets – you are feeding him/her for life.

In general, PWDs in Tanzania have problems in accessing corporeal or strategic needs and indeed all other aspects of life. For a long time, they have lived on the verge of destitution.

Access to Employment

Tanzania's National Strategy for Growth and Poverty Reduction categorises poverty into income and non-income poverty. The indices include insecure livelihood, poor infrastructure and income poverty. These are manifested in illiteracy, poor health services, poor nutrition and lack of water. Others are vulnerability to HIV & AIDS and environmental health.

General causes of poverty include environment; macro-economic conditions; governance (including political exclusion); ill-health; aging; cultural beliefs and practices. Disability is one of the issues related to the factors that cut across sectors and social groups and often negatively impact on income and non-income poverty. It is therefore sad to note that Cluster one of the National Strategy for Growth and Poverty Reduction which focuses on growth and reduction of income poverty – has only two points on PWDs:

- (a) Developing affirmative action to create employment opportunities for youth, women and people with disabilities.
- (b) Revamp closed and rehabilitate existing vocational training centres especially those that provide training for disabled

people and develop affirmative action and increased employment for disabled people.

Although this Strategy was launched four years ago, the above interventions are yet to be put in practice – thus denying PWDs economic gains. This is confirmed by the National Census report (2002) which states that:

...the proportion of persons with disabilities who are not economically active is significantly higher than the national average.

Also Mboya's research reveals that, by 2004 only 7% of PWDs were employed in the formal sector. Such a low employment rate can be attributed to lack of skills and negative attitude by potential employers. This shows that the Employment act of 1982 which was meant to uplift PWDs has served very little of its purpose.

Communication Aspect

According to the Convention on the Rights of Persons with Disabilities (2007), modes of communication include languages, display of text, Braille, tactile communication, large print and accessible multimedia. Others are written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.

In Tanzania, there are only two Braille presses – one used by the government for transcribing textbooks while the other belongs to the Free Pentecostal Church for transcribing Scriptures. These two presses can hardly cope with the demand. Of recent, a few institutions have attempted to introduce modern technology – albeit just for demonstration. Also, tactile technology is only available in less than four schools for the deaf/blind.

Through Tanzania Association of the Deaf, Sign Language has been introduced in the country. With the support of individual institutions particularly the University of Dar es Salaam, different

materials have been developed in this regard including a dictionary. Unlike Uganda, Sign Language is not yet recognised as an official medium of communication. So, even its promotion heavily depends on deaf people themselves.

Lack of information in alternative formats, has adverse effects on persons with disabilities particularly on grave matters like HIV & AIDS pandemic.

Participation in Politics

How easy is it for PWDs in Tanzania to join and compete fairly in electoral politics? To me, the prospect is quite bleak – especially when viewed from the National Strategy for Growth and Poverty reduction perspective. The strategy categorises PWDs and others as ‘vulnerable group’. The clause on reduction of political and social exclusion and, intolerance has the following strategy:

...designing and implementing campaigns to inform people of their rights, responsibilities, and address all forms of abuse, intolerance, discrimination and stigma. ... analysis of exclusion of vulnerable persons within key process (e.g. education, and health sector reviews) institution of reliable mechanisms of complaints of citizens to ensure people are protected from retribution and intimidation....”

This statement contradicts the self-representation philosophy and the logical contention that “when others speak for you, you lose” (Roberts, 1983: 7).

The National Census Report (2002) shows that only 0.5% of PWDs participates in elective politics. Unfortunately, the National Policy on Disability (2004) and the Constitution of the United Republic of Tanzania (1977) are also silent on this issue. Tanzania has a couple of Parliamentarians with disabilities but none of them has directly been elected by the ‘constituency’ of persons with disabilities. Two of them were appointed by the women wing of the ruling party – though the nomination is done by women with

disabilities. The other one was nominated by the President on unknown grounds. The rest are those fatally integrated, that is, becoming disabled late in life as incumbent parliamentarians representing respective constituencies.

The trend is not any better at the Local Government level. Neither does it at Civil Society level (religious institutions inclusive). There are sad stories that befell the few who attempted to vie for political positions at constituency level.

Future Prospects

It is obvious that PWDs in Tanzania still have a long way to go in order to realise civil realms. So, if the picture is this gloomy, is it that all is lost? Not really – I hasten to say – not all is lost. If the deficiencies identified above are addressed, there is a glimmer of hope. Concrete measures can be taken to tackle institutional barriers related to policy, legislation, development programmes and budgetary issues.

The National Strategy for Growth and Poverty Reduction proposed about twenty-two projects specifically targeted at PWDs. Previously, it was argued that these projects could not be implemented because of lack of data. Fortunately, the National Bureau of Statistics carried out a special survey on PWDs in mid 2009. This helped to put to rest the excuse of absence of data. Other positive developments are as follows:

- (a) Education – the government has heeded to the clamour by PWDs by responding as follows: first, calling for the review of the current Education and Training Policy (1995); and developing a nation-wide education programme specifically for promoting inclusive and Special Needs Education (in partnership with the government of Finland).
- (b) Developing the Social Protection Framework to cater for citizens in the vulnerable bracket.
- (c) Drafting of the disability act is underway.

- (d) Tanzania was among the first signatories to the Convention on the Rights of Persons with disabilities.
- (e) The current government is sensitive to disability issues – hence the political climate is conducive for dialogue.
- (f) The Land's act (1999) allows persons with disabilities to own land.
- (g) The Employment and Labour Relations Act (2004) forbids employers to discriminate employees on grounds of disability.
- (h) Great numbers of PWDs in the country are a potential force to assert for positive change once charismatic leadership is available and allies of all calibres a handy.
- (i) The Free Pentecostal Church of Tanzania has taken the lead in developing a pro-disability policy by which it could be held accountable and better still other religious institutions could emulate.

Conclusion

I will conclude by discussing the role of the church. The work of disabled activists could be a lot easier if Churches could join in. Churches who are credible the world over were instrumental in championing provision of education to PWDs. In Germany, Churches reviewed Scripture to make it disability sensitive. If this was possible in Germany, it is not a sacrilege if the rest of the Churches follow suit. Again, if the Churches in Tanzania and in many parts of Africa were in the fore front in introducing special education, they can also help in:

- (a) Reasonable accommodation – this means necessary and appropriate modification to rid society of uneven burdens that are placed on PWDs. This will ensure that PWDs enjoy equal rights and fundamental freedoms.
- (b) Universal design – this means the design of products, environments, programmes and services should be sensitive to the needs of PWDs.

Theological institutions that are increasingly becoming more inclusive can learn from the discourse in this chapter and probably use it in curricula.

CHAPTER TWENTY TWO

Persons with Disabilities in Uganda

Gidudu Balayo N. Seezi

Introduction

According to the population and housing census Report (2002), Uganda has a population of 24 million people. Going by the UN stipulation that PWDs make up 10 per cent of any population, the number of PWDs in Uganda can be estimated to 2.4 million.

Just like other countries, Uganda has different categories of PWDs. Common impairments include hearing, speech, physical disability, the visual, psychosocial disability, epileptic, those with learning difficulties, leprosy, loss of feeling and multiple disabilities.

The most dominant disabilities are physical (35.3 per cent), spine injuries (22.3 per cent) and the deaf (15.1 per cent). These are followed by visual impairment (6.7 per cent), difficulty in speech and conveying messages (3.9 per cent), mental retardation (3.6 per cent), psychosocial disorders (3.6 per cent) and others (9.6 per cent). At 4.4 per cent, our Northern region has highest incidences of disability. This can be attributed to the over twenty years of insurgency and fighting.

In general, the leading causes of disabilities include polio, mylites, trachoma, mental retardation, somatic hereditary defects and non-genetic disorders, wars, injury, accidents and malnutrition.

Models of Disability

Medical Model of Disability

Over the years, disability has been understood from the point of view of the medical model. This model as articulated elsewhere in this book states that impairment has traumatic physical and psychological effects on a person. It mainly focuses on the individual with an impairment. Once affected, such a person cannot have a reasonable quality of life through personal effort. In this definition, disability is perceived solely in terms of the physical, intellectual or sensory limitations, which makes a person disable or handicapped.

The medical model further postulates two options of handling the “problem of disability” so that PWDs can adapt themselves to the environment or society. First, the individual has to change on his or her own. Second, the individual must be rehabilitated with the help of professionals or curative medicine. This model totally ignores society’s handicapping effects on PWDs such as an inaccessible physical environment, negative attitude, insensitivity and open hostility. Society has neither recognised the significance of a white cane for the visually impaired nor accepted sign language as a basic medium of communication for the deaf.

Social Model of Disability

The social model of disability was developed because the medical model was considered shallow and inadequate. According to the social model, economic and social barriers hinder PWDs from participating fully in society. Unlike the medical model, it mainly focuses on barriers such as society’s disabling conditions, the environment and negative attitudes. This model stresses human rights not charity, solidarity not sympathy, respect not pity, participation in society and equity. This approach is liberating because, it gives PWDs identity, pride and a common cause. In contrast, the medical model is applied when developing services for PWDs. It is unfortunate that the theoretical basis of such constructs is charity and pity, with little regard to the views of PWDs, yet they are the beneficiaries.

Vulnerability of PWDs and Their Major Concerns

PWDs are generally defenceless because of their disabilities. They have to content with negative societal attitudes arising from ignorance, superstitions, neglect, fear and lack of awareness. As a result PWDs have inadequate access to social services and information. Their participation in socio-economic development processes is limited. Their major concerns are poverty, education and training, unemployment, conflicts and emergencies, social security, health, HIV & AIDS and accessibility. Gender and age also exacerbates the situation for PWDs especially when it comes to accessing services. These factors are discussed below.

Poverty

As argued elsewhere, poverty and disability are closely interlinked. Disability is both a cause and consequence of poverty. Disability has exposed PWDs to limited livelihood opportunities, and consequently led them into a state of poverty and vulnerability. The Government of Uganda has instituted measures to implement its Poverty Eradication Action Plan. However, the socio-economic situation for most PWDs is still characterised by abject poverty.

Education and Training

Under the Universal Primary Education (UPE) policy, government provides free education to all children in primary schools. There are 150,559 children with disabilities under this programme. Of this number, 82.53 per cent are boys while 17.47 per cent are girls.

Since 1967, approximately 4,500 PWDs have received training in vocational skills from vocational rehabilitation institutions. The special Needs Education (SNE) under the ministry of Education and Sports addresses issues of children with learning difficulties. Offered by Kyambogo University, these programmes play a key role in training teachers and other professionals in SNE and rehabilitation of PWDs.

However, the running of these programmes is not without fault. Appropriate teaching and learning resources are scarce, while trained staffs that can handle concerns of PWDs are inadequate. In addition,

most buildings and facilities at schools are not tailored to the needs of PWDs. The above, coupled with high costs of assistive devices and assistive services such as guides, helpers as well as interpreters are major factors that hinder PWDs from acquiring education. The same scenario is replicated in the area of skills training. Even the variety of skills offered in vocational rehabilitation centres are now limited.

Poor access to education in childhood would mean that a high proportion of PWDs remain illiterate and unskilled in adulthood. Therefore, access to education and training remains a key concern to PWDs.

Conflicts and Emergencies

Insurgency and civil strife that prevails in some parts of the country especially Northern Uganda has left many people with varying degrees of disability. In conflict and emergency cases, PWDs not only suffer the brute of the calamity, but are also often powerless. As a direct consequence of their vulnerability, they are excluded and marginalised when it comes to accessing emergency assistance. Emergency situations often undermine social patterns that support PWDs.

Employment

Given that most PWDs lack skills, accessing employment is a major challenge. Most employers do not give PWDs a chance to compete equally for employment opportunities even where they have the necessary qualifications and experience.

Consequently, a majority of PWDs are unemployed. The government has started a programme to sensitise employers to recruit qualified and skilled PWDs. But, this cannot yield significant positive results in the absence of a national employment policy that advocates equity.

Social Security

Because of either unemployment or underemployment, most PWDs in Uganda do not have access to regular income. A few that earn an income are self-employed largely in the informal sector. Existing social security schemes such as pension, provident fund and insurance services cover only PWDs in the formal sector.

Healthcare

The government has put in place regional referral hospitals, built new, and upgraded existing health centres and trained medical staff. However, despite the above efforts, PWDs still face several challenges. These include the high cost of health services, negative attitudes, unfriendly infrastructure and equipment designs, and long distances to health facilities. Therefore, the major concerns of PWDs remain their inability to access basic health services and assistive devices to enable them lead independent and productive lives.

HIV & AIDS

The HIV & AIDS pandemic has destabilised our social-economic fabric by reducing incomes at household level, increasing the number of orphans and straining health services. PWDs are sexually active. Because of their vulnerability, they stand a high risk of contracting as well as transmitting HIV & AIDS. Unfortunately, they are never targeted by most HIV & AIDS programmes. For example, PWDs have limited access to information, education, counselling services and antiretroviral (ARV) drugs. As a result, the impact of HIV & AIDS on PWDs remains unknown.

The government has put in place programmes focusing on public awareness, community mobilisation and employment. Unfortunately those with hearing and seeing difficulties do not benefit from these interventions. This is partly because the information that would benefit PWDs is not in accessible formats. As argued before, such information should be printed into large prints, Braille or sign language for interpretation. The situation is further exacerbated by low levels of literacy among PWDs.

Gender

Disabilities affect men and women differently but impact more on females than male due to social and cultural roles. Discriminatory cultural practices on property inheritance and property ownership affect the livelihoods of women with disabilities more adversely than men with disabilities. Government has put in place affirmative action to benefit all PWDs particularly women and girls. Other steps taken by government include the land policy laws on marriage and divorce, inheritance, domestic violence and other forms of violence against women and girls.

In spite of the above, lack of public awareness, negative community attitudes, cultural beliefs and lack of programmes on specific concerns of women with disabilities are still challenges.

Accessibility

In Uganda, PWDs face difficulties in accessing education, health, sports facilities, places of employment and other physical infrastructure. They are not able to access most buildings such as schools, hospitals and even courts of law. This is because many buildings do not have facilities such as ramps and lifts. Many lifts currently in use do not have talking devices to enable the blind to know which floors they are visiting. Also, roads do not have facilities for PWDs. In addition, PWDs cannot access information broadcasted by both electronic and print media. Limited accessibility to services that would also benefit PWDs has contributed to social exclusion of PWDs.

Disability in Uganda Before 1987

Before 1987, PWDs were not involved in the planning and implementation of programmes meant to benefit them. Mainstream disability programmes including construction of their buildings were designed in a manner reminiscent of lack of recognition and sensitivity to their needs. Where efforts were made, the services provided seemed to emphasise separation of PWDs from the community. They were also seen as a preserve for charity endeavours. These

actions obscured and isolated disability issues from the mainstream of society. They further divided PWDs along largely medical lines, created dependence on institutions, stifled individual initiative, and killed the morale, self-esteem and their confidence.

Formation of DPOs

The challenges faced by PWDs before 1987 led to the formation of an umbrella organisation called National Union of PWDs of Uganda (NUDIPU). The organisation was formed to act as a unified voice for PWDs in the country¹. Its immediate concern was to challenge the negative attitudes that hindered PWDs from participating in making decisions that concern them.

NUDIPU's vision is "A dignified Society for All" while its mission is "A unified voice for PWDs for the full realisation of their rights and inclusive development through support and advocacy." It aims to achieve its vision and missions through:

- Sharing and optimising knowledge and skills inherent in and among stakeholders.
- Advocacy and policy influence.
- Capacity building and enhancement.
- Awareness enhancement.
- Resource mobilisation.

Over the period this umbrella organisation has had numerous achievements which include:

- The mobilisation of PWDs to form cross disability coalitions (district unions and sub-county associations).
- Five members of parliament representing PWDs.
- Over 50,000 councillors with disabilities from local council 1 to local council 5.

¹Available at [<http://www.nudipu.org.ug/history.php>] accessed on 27 March 2010

- The existence of disability sensitive provisions in the national constitution and several Acts of Parliament.
- Because of NUDIPU's lobbying and advocacy work, PWDs have been mainstreamed in some government programmes. These include membership and participation in the following: National Agriculture Advisory Services (NAADS); Northern Uganda Social Action Fund (NUSAF) and Poverty Eradication Action Plan (PEAP).
- Some micro-finance institutions are extending loans to some PWDs who are deemed creditworthy.

In addition to NUDIPU as an umbrella organisation, a number of disability organisations each addressing the unique concerns of its specific membership have been formed which include;

- Uganda National Association of the Deaf (UNAD)
- Uganda National Association of the Blind (UNAB)
- Uganda National Action on Physical Disability (UNAPD)
- Mental Health Uganda (MHU)
- Epilepsy Support Association (ESA)
- National Union of Women with disabilities (NOWUDU)
- Uganda Parents Association of children with learning disabilities (UPACLED)

Information available at [<http://www.nudipu.org.ug/history.php>] states that these associations were in existence before. For example, UNAB was formed in 1970 and UNAD 1973.

All these disability organisations are mainly focused on advocacy. Apart from DPOs, there are other players engaged in addressing concerns of PWDs. We have for example, community Based Rehabilitation Alliance (COMBRA). Its main objective is to train community based rehabilitation (CBR) workers who in turn promote disability advocacy work at grassroots level within their communities.

The Negative Attitude toward PWDs

PWDs in Uganda have experienced the negative attitude that society in general has towards them. Those who are of Christian faith speak of similar negative attitude towards them by the church. This mainly entails feelings of dislike. The public perceives PWDs as unfortunate, bad, unlucky, useless, feared not respected, poor, illiterate, dependent, products of misfortune, beggars, dirty, unhealthy, cursed, dull, unproductive, aggressive, stigmatised, traumatised, abnormal, undesirable and incapable. Loss of limb, eye or ear does not completely hinder PWDs from doing what is expected of them as persons. Because of these attitudes, society readily offers PWDs 'fish' without teaching them 'how to fish.'

Causes of Negative Attitudes

- Society standards and norms.
- Expectations of a society from an individual.
- In as much as we are all unique, a 'normal' person is supposed to conform to certain qualities.
- Ignorance – meaning lack of knowledge about PWDs because of poor communication, exposure or lack of interaction especially with individual PWDs.
- Personal judgment – many people are wont to make snap judgments. For example, because somebody is crawling, he or she is mistaken as lacking in understanding.

Testimonies of Instances of Negative Attitude

Below are some testimonies that without doubt stem out of the negative attitude towards PWDs.

- Some disabled women reveal that men only make advances on them at night, and when visiting leave before dawn to avoid being seen in public. Whereas they wish the men would accept them as spouses, the fear of the men is 'what will people say?'
- A colleague of mine told me how he turned down a girl who he was sure could make a good wife just because she was disabled.

He opted for an able-bodied woman, never experienced peace and later divorced her in the end. Today, now in his sixties, he lives alone.

- Disabled women conceive and attend antenatal clinics. Some testify that when they visit clinics many a nurse are wont to ask ‘Eh! How did you become pregnant?’ forgetting that women with disabilities function normally.
- My wife is a teacher. She told me of a story where they were having a chat during their break time. A male staff member suddenly quipped that he ‘sympathised with women who have married disabled men.’ And this he did, knowing very well that my wife who was present during the conversation is married to me – a man with disability.
- Many PWDs have testified that their parents never gave them fees to go to school. Some parents think that a child with disability cannot study.
- When I was enrolled at college for my theological studies, my colleagues would wonder albeit in murmurs, “How is this man going to manage parish work!”
- I at one time represented PWDs on Local Council 5 in my District as their councillor. I later learnt that one honourable councillor who is able-bodied wondered how a PWD like myself would speak during council debates.
- A teenage with disability was denied entry into one of the famous night clubs in Kampala because of his disability. He went to court and filed a case citing discrimination. The judges ruled in his favour, and he was subsequently compensated in monetary and a public apology.
- A young man with physical disability stopped a taxi (*matatu*) at a bus stop. However, in the process of boarding it the taxi conductor pushed him and he fell and sustained serious injuries. The conductor later claimed that he was delaying them.

Steps Towards Removing Negative Attitudes

By and large, the negative attitudes towards PWDs are on the decline because of some of the following measures that have been put in place.

- PWDs are recognised as human beings hence, the various legislation in place to protect them.
- PWDs are accepted as part and parcel of society. They have representatives at various levels of governance.
- The Government has put in place a national policy on disability that provides the framework for responding to the concerns and needs of PWDs. It has clear laid down with guiding principles.
- The various DPOs have done a lot of advocacy work through awareness raising and sensitisation on disability issues.

Cultural Practices that Affect PWDs

Traditionally, most cultural practices among various ethnic groups in Uganda treated PWDs as inferior. For example, having a PWD born in a family was seen as a bad omen. This explains why a disabled child was kept in seclusion. Visitors to a home were not supposed to know that there is a disabled child. Also, when parents died, it was very rare to hear that a PWD has been made heir.

In the past and to some extent today, a disabled person would not be considered when family land is being shared to the children – especially male as is the custom. In most cultures, the family pays dowry for a son who is ready to marry. The belief by most families is that a disabled person cannot marry and raise children.

In my own ethnic group, a PWD is referred to as *watoya* meaning someone who is useless. This means that a PWD cannot be accorded equal treatment like the others who are able bodied. However, modernity has reduced the stigma placed upon PWDs by culture as discussed under legal provisions.

Constitutional Provisions on Disability

1. In Uganda there are national laws concerning PWDs made with the following objectives in mind.

- (a) To provide legal protection for PWDs in service provision.
- (b) To eliminate all forms of discrimination against PWDs.
- (c) To provide a framework for equalisation of opportunities to PWDs.
- (d) To consolidate the laws governing individual employment relations.
- (e) To enhance employment, participation and protection of rights of PWDs.
- (f) To guide and inform the planning process, resource allocation, implementation, monitoring and evaluation of activities in respect to PWDs' concerns at all levels.

2. The 1995 Uganda constitution has specific provisions on disability with the following provisions:

- (a) Objective (VI) of the constitution ensures gender balance and fair representation of marginalised groups on all constitutional and other bodies.
- (b) Objective (XXIV) provides for promotion of sign language for the deaf.
- (c) Article 21(2) provides that a person shall not be discriminated against on the ground of disability.
- (d) Article 32(1) provides that the state shall take affirmative action in favour of groups marginalised on the basis of disability.
- (e) Article 35(1) provides that PWDs have a right to respect and human dignity and Article 35(2) provides that parliament shall enact laws for the protection of PWDs.
- (f) Article 59(4) provides that parliament shall make laws to provide for the facilitation of citizens with disabilities to register and vote.
- (g) Article 78(1) provides that parliament shall consist of the representatives of PWDs.
- (h) Article 78(2) provides that after every five years parliament

shall review the representation of PWDs to parliament for the purpose of retaining, increasing and abolishing the representation.

3. The children's statute, 1996

(a) Section 10 of the statute focuses on children with disabilities and states that parents of children with disabilities (CWDs) and state shall:

- (i) See that the children with disabilities are assessed as early as possible.
- (ii) Offered appropriate treatment.
- (iii) Provide facilities for rehabilitation and equal opportunities to education.

(b) Section 11(5) provides that the local government council shall keep a register of disabled children within its areas of jurisdiction.

4. The Local Government Act, 1997

- (a) On the composition of district councils PWDs are represented by two persons (one man and one woman).
- (b) PWDs are represented at lower local government council LC III or Division as at District level that is two (2) councillors – one (1) woman and one (1) man.

5. The Land Act, 1998

- (i) Section 28 provides for the rights of PWDs in respect to customary land. It provides for access to ownership, occupation or use of land.

6. Rules of Procedure of Parliament, 1996

- (i) Allows any person who is not a member to assist a member who is a PWD in the house of committee.
- (ii) Allows a member who is a PWD to bring into the house

crutches or any other aid needed owing to his or her disability so as to participate in the proceedings of House or Committee.

7. The Uganda Communication Act, 1998

Section 8 provides for research into the development and use of new communication techniques and technologies to allow accessibility by persons with hearing impairment to communication services.

8. Uganda Traffic and Road Safety Act, 1998

- (i) Section 42 provides that no person with disability shall be denied a driving licence by reason of his/her disability.
- (ii) Section 132 provides for use of bells, alarms, direction indicator to access PWDs to roads, railways and airports.

9. UNISE ACT, 1998

This Act provides for the establishment of Uganda National Institute of Special Education (UNISE) training of teachers for children with special needs, training special education teachers, official recognition of the UNISE structure with people of disabilities represented by NUDIPU on the UNISE governing council.

10. The Movement Act 1998

It provides for representation of PWDs as follows.

- (i) At all lower levels PWDs are represented by councillors who are themselves PWDs.
- (ii) At National level 5 MPs
- (iii) At Movement National Conference.
- (iv) At National Executive Committee of the Movement.

These representatives of PWDs have made profound positive impact in influencing the making of laws and policies to promote disability issues like employment opportunities for PWDs.

The PWDs Act 2006

Part III of the Act specifically talks about the employment of PWDs. Article 12 (1,2) prohibits discrimination in employment on grounds of a person's disability in regard to any job application, procedures, hiring, promotion, employee compensation or job training among others.

Article 13 of the same Act states that PWDs have a right to practice their professions and to carry on any lawful occupation, trade or business of their choice.

Article 14 is against discriminative medical examination.

Article 15 talks about discrimination against disabled employees.

Article 16 calls for accessible working environments for the disabled.

Article 17 provides that employers who employ 10 or more PWDs will be awarded tax reductions.

The Employment Act 2006

Section 20 (1) (f) requires a commissioner in the labour ministry to publish an annual report showing the statistics of PWDs in the work place and any aids being provided by the employer.

Section 21 (1) (d) provides for a representative of the disabled on the Labour Advisory Board (LAB).

Section 24 (g) prohibits termination of contracts of PWDs on the basis of their disability.

Section 27 (1) (f) calls for the minister to make regulations for the employment of PWDs to end the provisions of the employment Act.

The Equal Opportunities Commission Act 2007

This new Act has a preamble which calls for equal opportunities and elimination of discrimination and other inequalities against the disabled. PWDs have a representation on the commission. The commission is among others required to take affirmative action to promote employment opportunities for PWDs.

The Policy on Disability

This policy on disability is aimed at contributing to the improvement of the quality of life of PWDs through the scope of expanding interventions. The policy ensures that the Central Government, Local Governments, CSOs, parents and caregivers involve PWDs in all initiatives that are meant to improve their wellbeing.

The Local Government (Amended) Act 2001

Section 55 provides for the representation of PWDs on;

- (i) District Service Commission.
- (ii) District Tender Board (in 2006 this ceased to be a political committee).

The Universities and Tertiary Institutions Act 2001

The Act provides for the establishment of the National Council for Higher Education which shall consist of one PWD appointed by the minister. Section 28 provides for affirmative action in admission to public universities.

A Critique of the Laws

It is important to note that whereas the above Laws and Acts are in place, not all PWDs are aware of their existence. Neither are the laws being implement to the letter. For example, the government owned television *Uganda Broadcast Corporation (UBC)* stopped sign language services on its news broadcasts contrary to the Disability Act. Perhaps another consideration is to translate information into the major local languages in order to create user friendly information packages on legislation and human rights.

The National Council on Disability is the organ supposed to implement these Laws. However, it is still new and is not capable of fulfilling its mandate. Therefore although Uganda has some of the best disability policies in the world, PWDs are yet to fully access their rights as citizens. For example, the Employment Act has gaps that inhibit employment opportunities. Situations where discrimination

occurs are considered only when persons are already in employment. This excludes what happens at the recruitment level.

Although there is provision for PWDs on the LAB, the Board is not yet functional. Similarly, there is no provision on how the representatives are to be chosen. The Act has been disseminated in mainly the formal sector, yet the formal sector is the biggest employer. Although a prohibition against discrimination in employment exists, there is no authorisation for employers to reduce it. The measures that ought to be taken by employers are not specifically mentioned. An example would be a condition for mandatory action such as requirement for modification of buildings.

The way forward especially in employment would among other things require a policy in place regarding disability at the workplace. Then other issues like, affirmative action in employment of PWDs and criterion for choosing representatives of PWDs on the LAB would follow.

Church and Disability

A majority of PWDs in Uganda are Christians, many of whom are either Catholics or Protestants. The Catholic Church has established homes in which it takes care of PWDs. These are called Cheshire homes. The children with disabilities in these homes are placed in primary schools close to these homes. They assist these children with learning materials such as books, pens and bags. These homes include Butiru, Nkokonjeru and Budaka.

Those PWDs who are adults are taught skills in handicrafts, carpentry and cobra trade among others. Most beneficiaries are those with physical disabilities.

Young children with physical disabilities are assisted to receive corrective surgery in hospitals. The disabled in these homes are provided with assertive devices as an aid to their mobility such as wheelchairs, callipers and surgical boots.

However, at end of the day when, these disabled leave these homes and return to their homes, they are not so much attached to

the church. It is highly probable that while at these centres, little is done in ministering to them in the spiritual aspect.

Protestant Church

With the Protestant Church to which I belong, there is nothing like a designed and coordinated plan of reaching out to PWDs. If a diocese or a single parish has a programme to benefit PWDs, that arrangement is at individual level.

Namirembe Diocese found in central Uganda which belongs to the Church of the Province of Uganda has set up a desk at the Diocese level for PWDs. However, this is not replicated in its parishes. The Diocese has ordained two clergy who are of hearing impairment.

St. Andrews Cathedral Church urban located and found in Mbale Diocese has provided a room where the deaf meet for worship. Unfortunately, it is not the clergy in this church that conduct service. PWDs do it themselves. The parish does not even facilitate the sign language interpretation not because they lack funds, but possibly because they do not think it is very necessary. I have on several occasions personally pleaded with them to mainstream the deaf in the main congregation to no avail. Surprisingly, whenever I seek to find out why this is not possible, there is no justified reason given apart from saying well, 'we shall look into the matter.'

Most of the churches lack ramps. It is very difficult for PWDs in wheelchair to access them. Also, some disabilities especially of the physical nature may be so severe that one may not be able to move to the altar, kneel and receive the Holy Communion. Yet, there are no special arrangements for such people.

Other churches like the Latter Day Saints have assisted PWDs by providing them with wheelchairs. Truly, this is a good gesture, but the church does not seem to bother whether these beneficiaries go to church or not at all. A friend of mine who is disabled, a graduate and a civil servant in government once attended a crusade organised by one church in Kampala. He attended, just like the other Christians who turned up to listen to the word of God. After preaching, the

pastor said he was going to pray for a healing so that even the ‘lame’ would walk. As he started for the podium, some people came and kicked off his white cane. Among them were organisers of the crusade whom my friend highly believed. As he fell on the ground, they surrounded him shouting, God was ready to heal him. They asked him to continue praying in faith when he returned home so that God heals him. He got embarrassed and swore to me that he will never again go to attend a crusade.

My personal experience as a priest is that very few PWDs go to church. I have approached several to ask why this is so, and the answer by most is:

When a disabled person goes to church, most clergy/pastors have a thinking that is unconsciously passed to their congregation. It is that their prayers cannot get us healed because we lack faith in our belief. This makes us uncomfortable and the best is to keep away

I have already referred to the case where colleagues questioned how I could manage parish work given my disability. Perhaps they were thinking how I could transverse the whole parish crossing rivers and valleys in the course of doing my work. They could have had presiding over burial funerals in mind. They failed to hardly acknowledge that ministry work is diverse. Indeed, any trained PWD cannot lack placement to serve the Lord. To date, when it comes to making transfers of clergy, it is like the staffing board finds it not easy to place me. This, in my opinion is just unfounded bias or negative attitude based on my condition.

Conclusion

This Chapter has given two definitions of disability namely the medical model and the social model. The different types of disabilities and some of their leading causes are mentioned. PWDs in Uganda are estimated to be 2.4 million, and they are vulnerable in a number of ways. It also discusses DPOs and their role. The negative attitude towards PWDs, testimonies of those who have been subjected to

negative attitudes and how culture perceives disability are also discussed. The Chapter has provided provisions on disability in the Uganda Constitution, 1995 and finally considered the church and disability.

CHAPTER TWENTY THREE

Persons with Disability in South Africa

Joy Sebenzile P. Matsebula

Introduction

In this Chapter, I approach the subject of PWDs in South Africa using my life journey as a point of reference. I have done so because my life experience covers all aspects of disability I consider important. Having lived for 50 years as an African black woman with disability, I find it pleasurable to engage with a seminal topic that has evaded even the church for many years.

Consequently, the improvement of the conditions of PWDs has been negated in the psyche of communities, both at national and international levels. PWDs are people first. Disability is a secondary factor that has a limiting effect in their lives. Of the major issues facing humanity, human rights and equality have been most profound. I am glad to note that disability is also under debate.

Challenges Facing PWDs

Having lived through the era of disempowerment in the 1950s, I cherish the post-apartheid government and the new political dispensation because of the opportunities available for PWDs. I am privileged to live in this new era. Hence, I always use any opportunities that come my way to contribute to the development of the nation and the region at large. Of course, issues of disability are closer to my heart. PWDs in South Africa face many challenges as discussed below.

Attitudes

In the beginning, many institutions for PWDs were built on the model that disability is a medical and welfare issue and were run by missionaries. This meant that their basic role was to “look after” and “provide for” PWDs, thus creating a dependency syndrome. They were pitied and perceived as a curse to the family. This undoubtedly caused distress to the lives of family members.

Cultural Practices

Similarly, some cultures strongly believed that children born with disabilities were a curse to the family and to the community. Consequently many myths were made up to explain their condition. For example, there is a myth that albinos do not die, so they are not to be buried because they simply disappear in the forests and mountains. Also, there is the tragic and fatal belief that if a man rapes a PWD and particularly a child, then he will be healed of HIV& AIDS.

Till today, PWDs are not accorded due respect and dignity befitting their status in many families. They are not involved in the decision making process in the family – even if they are the eldest. This can be attributed to the wrong notion that PWDs are also mentally disabled and therefore unable to make sensible decisions. What this does is that it creates a division in the family. It is an outright violation of the basic human rights of PWDs and, greatly undermines their intelligence.

My Story

We are seven in the family, though I am the only one with a disability. When I was growing up in the 1950s as a child, my parents faced a dilemma about my physical condition. Both were teachers who believed strongly in the value of a high quality education for all regardless of sex or disability. For my parents, the serious resource constraints at that time made this particularly difficult since they had to decide whom to give preference in education.

My parents believed that I should attend a mainstream school in order to be able to cope in a non-disabled world. Since there was

no separate world for PWDs, they believed that isolating me by enrolling me in a “special school” would not adequately prepare me for the real world. So, the family had to move from South Africa to Swaziland where I attained my primary and high school in a mainstream school. I later proceeded to acquire university education in Botswana, the United States and finally Canada.

The decision my parents made to take me to a mainstream school to me is evidence of a paradigm shift that they took back then. It was a step away from the usual process of having a disabled child educated in a special school. My parents lived the paradigm shift without any academic analysis or definition of it.

Paradigm Shift

The government has undergone a paradigm shift in its approach to disability issues. It’s reversal from the welfare, charity or medical approach to a more human rights and social development perspective has changed the conditions of PWDs in South Africa.

The government has instituted the Integrated National Disability Strategy (INDS), which provides guidelines for mainstreaming disability in South Africa. However, this remains merely a framework to guide the integration process. It does not sanction the implementation the guidelines and ensure that they are adhered to. But, as we shall see later, Acts such as the PEPUDA and Employment Equity Act provide for the enforcement of the INDS. With the advent of the UN Convention of PWDs there will have to be a Disability Act to enforce regulation.

Public Policy and Legislations for PWDS

South Africa has some of the best developed, meaningful and substantive government policies on disability in the world. Many countries, even in the developed world have replicated these policies which are considered world class. However, full implementation has not yet been realised. I remain optimistic that with time and planning, this will be also achieved.

South Africa has developed policies and legislations that target four key areas: accessibility, education, health and employment or economic empowerment. Below is a synopsis of these policies, strategies, acts and regulations.

Accessibility

The Constitution of the Republic of South Africa No. 108 of 1996 – provides that everyone has the right to have access to social security including if they are unable to support themselves or their dependants. It obligates the state to take reasonable measures to enable PWDs achieve these rights.

The Social Assistance Act No. 13 (2004)

The key objectives of the Act are to:

- (a) To provide for the administration of social assistance and payment of social grants;
- (b) To make provision for social assistance and to determine the qualification requirements in respect thereof;
- (c) To ensure that minimum norms and standards are prescribed for the delivery of social assistance; and
- (d) To provide for the establishment of an inspectorate for social assistance.

The Agency administering the social assistance is also obligated to:

1. Offer all reasonable assistance to a person, who due to his or her age, a disability or an inability to read or write, is unable to understand, appreciate or exercise his or her rights, duties or obligations in terms of this Act, in the official language of the Republic which he or she is likely to understand.
2. Out of moneys appropriated by Parliament for this purpose or with funds donated for this purpose, publish and distribute to beneficiaries and potential beneficiaries, brochures in all official languages of the Republic setting out in understandable language the rights, duties, obligations, procedures

and mechanisms contemplated in this Act, as well as contact details of the Agency or anyone acting on its behalf.

Building Standards Act No. 103 (1977)

The Act, last amended in 1989, is the enabling Act under which the National Building Regulations are made. It provides a framework within which the Regulations can be administered, monitored and enforced. The Act and Regulations must therefore be read together.

The National Building Regulations

Made by the Minister of Public Works in terms of Section 17(1) of the Building Standards Act, aim to ensure that buildings are designed and built to be safe, healthy and convenient for users.

The SABS 0400 Code of Practice

A non-statutory set of guidelines giving technical information for the practical application of the National Building Regulations. The legislation governing accessibility of the built environment has primarily relied on the application of one aspect of the Regulations, Part S, which was introduced in 1985 to address the needs of PWDs.

Universal Access

It means the removal of cultural, physical, social and other barriers that prevent PWDs from entering, using or benefiting from the various systems of society that are available to other citizens.

The Constitution of the Republic of South Africa No. 108 (1996)

The Constitution of the Republic of South Africa, specifically section 9(3), provides a strong basis for new policies and legislation aimed at reducing unemployment and poverty, especially amongst historically disadvantaged individuals such as PWDs. This section of the Constitution states that “the state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, pregnancy, marital status, ethnic or social

origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth”.

The Integrated National Disability Strategy (1997)

With respect to disability, one of the most important achievements of the post-apartheid government has been the development and adoption of an *Integrated National Disability Strategy (INDS)*. One of the primary objectives of the INDS has been to facilitate the inclusion of disability related issues into every aspect of governance. The INDS identifies key areas affecting PWDs and provides policy objectives, strategies and mechanisms for each area.

The Promotion of Equality and Prevention of Unfair Discrimination Act (2000)

This act deals with the prevention, prohibition and elimination of unfair discrimination, hate speech and harassment. In terms of disability, the Act addresses issues around environmental accessibility as well as reasonable accommodation in the workplace. According to this Act, neither the state nor any person may unfairly discriminate against any person on the ground of disability, including:

- (a) Denying or removing from any person who has a disability any supporting or enabling facility necessary for their functioning in society;
- (b) Contravening the code of practice or regulations of the South African Bureau of Standards that govern environmental accessibility;
- (c) Failing to eliminate obstacles that unfairly limit or restrict those with disabilities from enjoying equal opportunities, or failing to take steps to reasonably accommodate their needs.

Education

White Paper 6 on Special Needs Education (2001)

The White Paper on Special Needs Education (SNE) provides a framework for government's long-term goal to achieve an inclusive

education and training system. This process will investigate and address barriers to learning, and recognise and accommodate the diverse range of learning needs. It is part of a twenty-year programme that aims at building an open, lifelong and high quality education and training system for all citizens, including those with disabilities.

Health

National Health Act No. 61 (2003)

The National Health Act obligates the state to provide a structured uniform health system where vulnerable groups such as women, children, older persons and PWDs are eligible for free health services at public health establishments.

The Mental Healthcare Act No. 17 (2002)

The Mental Healthcare Act recognises the right of every mental healthcare user to be treated with respect, dignity and due consideration for what is in the best interest of the person. Chapter 3 of the Act prohibits unfair discrimination, exploitation and abusive treatment on the basis of mental health status. Unless the person is incapacitated, the healthcare provider is obligated to inform the user of his/her rights before the commencement of treatment.

Employment or Economic Empowerment

The Employment Equity Act No. 55 (1998)

In 1998, the Employment Equity Act (EEA) was passed by the South African Government. The Act recognises that PWDs are unfairly discriminated against in society and in employment, because of widespread ignorance, fear and stereotypes. In addition to prohibiting unfair discrimination, the Act requires the implementation of affirmative action measures to ensure that certain groups: namely blacks, women and PWDs are adequately represented in the workplace. For PWDs, for example, this is to be done by providing

reasonable accommodation. The *Commission of Employment Equity* (CEE) was established with the aim of monitoring, evaluating and advising the Minister of Labour on the implementation of the Act.

The Code of Good Practice on the Employment of PWDs – produced in 2002, as part of a broader equality agenda for PWDs to have their rights recognised in the workplace. The Code is to be read in conjunction with the EEA and serves as a guide to employers on how unfair discrimination can be avoided and employment equity achieved, from recruitment to termination of employment.

The Technical Assistance Guidelines (TAGs) on the Employment of PWDs – produced in 2004, these guidelines are intended to complement the Code of Good Practice and to assist employers in the practical implementation of their obligations towards PWDs as set out by the EEA. The TAG provides a practical step-by-step guide to implementing the measures for employment equity contained in the Code. The TAG draws on international best practice models and highlights case studies of employers, employees, trade unions and PWDs across South Africa.

The Skills Development Act No. 97 (1998)

The Act provides a framework for improving the skills of the South African workforce through national and local workplace strategies. This process includes: (1) an expanded number and range of learnerships leading to recognised occupational qualifications; (2) learnerships designed to assist PWDs to either work in the formal sector or create self employment. The Act also advocates for additional post-qualification support services. In 1999 the Skills Development Levies Act was passed to obligate employers to pay 1 per cent of their workers earnings as a Skills Development Levy each month. These funds are to be used for workplace training.

The Preferential Procurement Policy Framework Act No. 5 of 2000 - This is a piece of legislation that aims to enhance the participation of PWDs and small, medium and micro-enterprises in the public tendering system. This works by using a points system and specific goals to give tender contracts to people or categories of people historically disadvantaged by unfair discrimination. Under this system, a contract will be awarded to the bidder with the highest number of points.

Parliamentary Representation

South Africa now has the largest number of PWDs as politicians in Parliament. These are both at Provincial and National Legislature. This has had a major impact on the lives of PWDs in SA.

Likewise some institutions and organisations have also taken up the challenge posed by government to mainstream disability and have appointed PWDs at strategic leadership and management levels. These are as follows:

Chapter 9 Institutions

- Human Rights Commission
- Gender Commission
- Youth Commission

Parastatal institutions

- South African Broadcasting Cooperation
- ESKOM – power utility
- TELKOM – telecommunications utility

Government

- Provincial structures
- Local structures

Also, SA has not shied away from reminding employers not to focus on employing PWDs at menial jobs. Rather, they are encouraged to look for PWDs with potential, develop their skills and hire them at even medium to higher level management positions.

Services Offered Through Various Providers

Apart from legislation, some of the best services for PWDs are available in SA particularly if one has the necessary resources. Even though, public facilities do provide basic facilities. When a person with an injury leaves a hospital and cannot walk, he or she is entitled to a wheelchair. Extra resources become a necessity, if the wheelchair does not meet specific requirements. Those who can afford can get the best model of a wheelchair available on the market.

The government also provides tax breaks for PWDs purchasing or importing vehicles. A tax break is also provided for the hand control that may be fitted to enable a PWD to drive. Likewise a person with hearing impairment is given a hearing aid. However, batteries of sustaining it are very expensive for the average deaf person.

Rehabilitation services are also provided by both government and the civil society. Many of the registered bodies are subsidised by government. There are a range of such facilities. So, access to quality services is determined by the resources one has. This is true of all services in the country.

The Impact on PWDs

The government has been at the forefront of ensuring that PWDs lead the debate on issues relating to them and all societal development issues. This has led to the development of effective and meaningful disability inclusive and specific policies, strategies, programme and projects. A visit to the government website will reveal a whole plethora of substantive acts, bills and strategies. During the development of these documents, PWDs were extensively consulted.

However, this process of consultation was done at a great cost in terms of time, finances and other resources. Political leadership and the government were committed to the emancipation of PWDs. They saw the urgency to recognise and respect the rights of PWDs as full citizens and budgeted for and provided required resources.

By the time the development of the UN Convention started, South Africa was well ahead with regard to policy. It gave support to the motion by Mexico that the UN starts discussions on the topic. It then led other African countries in providing leadership throughout the development process. I played that leadership role as a participant from 2001 until 2005 when I left government employment.

The successes of these initiatives can be looked at from two main perspectives: the government's perspective in advancing rights of PWDs and the perspective of the ordinary person on the street with a disability.

Whilst government actions have gone a long way in addressing disability issues, the ordinary PWD still experiences challenges in their daily lives. To a greater extent a lot of the achievements made are at a policy level. This is very important as it forms the basis for their socio-economic emancipation. However, the challenge now is in service delivery and realising those rights in real terms, not just policy.

This is evident because the excellent policies availed have failed to achieve some targets. For example, the government set a quota that from 2000 to 2005, it would ensure that PWDs would constitute 2 per cent of the private workforce. However, by 2004 it was evident that the target would not be met. There are many reasons for this failure, the main being that the public system is very poor particularly in providing the needs for PWDs. PWDs were employed, but unprofitably. Most of their income was spent in commuting from home to work and vice versa. In addition, they faced indignity in the process. For example, it is dehumanising to be lifted from your wheelchair and put into a vehicle, whilst your wheelchair is thrown into the vehicle. Most likely, the wheelchair is damaged in the process.

PWDs then decided that it was easier and more cost-effective to remain at home and receive the disability grant.

Inevitably, the disparity in resources therefore means that the majority of the population of PWDs who are black are unable to access services. This is especially true when compared with better resourced race groups and other black people. It is therefore, not surprising that the ordinary PWD in the street thinks that their situation is very difficult. Areas of concern are and include employment and access to other resources, churches, social life and discrimination. All these challenges exist in spite of the anti-discrimination law.

People with Disabilities in the Church

I have spent much of my life active in my spiritual journey. I have observed the disparity in the recognition of disability as a human right and social development paradigm in the Church. This has been a great injustice to PWDs. I am glad to note that the Anglican Church in South Africa, of which I am a member, ordains women and PWDs. This they have been doing for a long time now – as other churches continue to debate the issue.

Whilst there are many allies in the disability movement; it is important for the church to appreciate that PWDs must have the right to articulate their own issues. This is a stand we cannot compromise if we are to talk about *Doing Theology from Disability Perspective*. Like all other churches in the world, many SA churches have not openly acknowledged their role in addressing disability. The church has not accepted that disability is a human right that requires mainstreaming in *all respects*. It should not look at PWDs as agents that need to be prayed for to receive healing.

Economic Empowerment of PWDs

The Disability Employment Concerns (DEC) Trust was established in 1996 by seven major South African national Non-Governmental Organisations representing PWDs. It was started with full support from the Minister in the Presidency Dr Essop Pahad due to the foresight of the leadership of the disability movement.

The minister is responsible for disability in government at national level. DEC provides a vehicle for the empowerment of PWDs. It is an empowerment investment trust established to engage in business ventures in the context of Broad Based Black Economic Empowerment (BBBEE).

Thus, one of the most economically liberating experiences that PWDs in SA have had is the implementation of the BEE and BBBEE policies. The policy stipulates that in order for any business to have legitimate trading value in SA, it must have an empowerment partner. This applies whether it is a local or international company and particularly if it plans to trade or do business with the government. I personally benefitted from this government policy through strategic partnership with a Platinum Mining Company of women that needed a PWD to boost their score card ratings. The full details of this policy, just like other government policies can be found on the government website. There are many categories of these empowerment partners; among them PWDs and women with disabilities.

The government strongly encourages and incentivizes women to participate in business development and transactions. One of these incentives is creating the space to enable women to participate meaningfully in business ventures as defined by the BBEE and the BBBEE policies.

For me this is a real and sustainable means of ensuring that PWDs move from political liberation to economic liberation. You may be politically free but if you and your family are hungry, the liberation is rather superficial and cannot be sustained. This principle has worked very well in favour of PWDs. I am a living example of the success of such strategic partnerships.

Personal Experiences

I have already mentioned that I was born in South Africa and grew up in Swaziland. I studied in Botswana, Canada and the United States of America. I was born into the Christian faith, baptised as a child and confirmed at adolescence.

From an early age, I was allowed to grow as any other child in the family. I was therefore aware that if I wanted change to make my life easier be it at home, church or school I had to speak up. This gave me a sense of responsibility for my actions. I never used my disability as an excuse for not performing well at school or achieving any goal

My vision in life is to work towards an inclusive society. For me, inclusion means ensuring that PWDs such as myself realise their full potential whilst enjoying the rightful place as full citizens in society. It is also about using our diversity to create a dynamic and successful society that is responsive to the needs of various categories of people.

I became a member of the disability movement in 1986. I was part of the Southern African regional leadership that worked towards influencing the change of the disability model from “charity and welfare” to “social development and human rights”.

I started work as a research officer in Biometry. From July 2005, I worked as the Executive Director of the African Access Group of companies. I was responsible for communications of the Group and for business development initiatives. My primary motivation for taking office was because the vision of the company fitted my own vision of empowering marginalised sectors of our society through empowerment. In this new portfolio, I was able to continue providing leadership in numerous processes that promoted the rights of PWDs.

Whilst serving in all these positions I was active not only in the disability movement in the Southern African region, but also internationally.

I started work in the disability sector in 1997 when I joined the Office of the then Deputy President Thabo Mbeki. I was employed in the Office on the Status of PWDs. This office was tasked to pioneer the integration of disability into mainstream society. My principal mandate was to provide strategic leadership in mainstreaming disability through integration. This was to ensure that the principles of the equalisation of opportunities for PWDs were realised.

It was a very exciting period as there was no other office existing anywhere in the world where we could learn from. The establishment of the office came through the efforts of PWDs themselves who formed part of the political struggle against apartheid. This formed an excellent alliance to bring unity into the agenda of the liberation struggle and subsequently to the reconstruction and development programme (RDP).

In 1999 my office moved to the Presidency and was accorded status as a key development organ that government would use to promote the rights of PWDs. It was during this time that I was able to undertake the following activities:

- Participate in the development of the UN Convention on the Rights of PWDs – I led the South African delegation from 2002 to 2005 in this process.
- Coordinate an awareness and education programme to create an understanding among public workers on mainstreaming disability and implementing numerous advocacy programmes.
- Coordinate a public awareness campaign on the rights of PWDs – implementation of a public education and awareness raising project,
- Coordinate the passing of INDS which continues to guide the integration of PWDs into mainstream society. The specific protocols it calls for has made it more effective as opposed to disability policies in many African countries, which lack implementation strategies. Now that SA has ratified and signed the UN Convention on the Rights of PWDs, we look forward to developing a disability specific policy.
- Provide guidance and advice to the political leadership on disability matters. The political leadership had already committed itself to the cause. Therefore, my work was greatly enhanced and enjoyable. The Minister in the Presidency who had the political responsibility for the programme was an outstanding supporter of PWDs and

their cause. His contributions went a long way in enabling the disability movement achieve what it has accomplished over the years.

Other Achievements

My other achievements have been in six core areas:

- Business development – the development of business units with a focus on women with disabilities. Also, development and implementation of an economic empowerment project for PWDs.
- Providing leadership roles in the mainstreaming of disability in all sectors of society.
- Developing and presenting conference papers – implementation of international events as the main event organiser.
- Establishment of a Disability Studies course at University of Cape Town (UCT) – the development of a training programme.
- Training.
- Participating in international partnerships and consulting services for the United Nations.

Present

In the recent past I have been instrumental in the coordination of disability audits, the development of the African Decade of PWDs and the United Nations Convention on the Rights of PWDs. I have also served as an advisor to national, regional, international and United Nations agencies on development work. These include:

- The World Bank,
- United Nations Association of International Systems,
- World Health Organisation (WHO)
- International Labour Organisation (ILO)
- Scandinavian governments

- The government of Italy
- The South African Disabled Women's Development programme
- The MERAKA African Advanced Institute for Information & Communication Technology
- South African Qualifications Authority.

I have further had the opportunity to contribute to the writing of articles in the media, newsletters and books. In addition, I have been a member of several management boards as shown in the table below:

Table 25.1: Board Memberships

Dates	Organisation
1995 to date	<i>Action on Disability and Development</i> – an international organisation based in the United Kingdom, which provides financial and technical support to grassroots organisations of the disability movement.
2002-2006	<i>Telkom Foundation</i> – a subsidiary of the Telkom Company, which served as the only fixed line operator in South Africa. The Foundation services the social responsibility of Telkom.
2006 to date	<i>The Disability Employment Concerns (DEC) Trust</i> – established in 1996 by seven major South African national Non-Governmental Organisations representing PWDs. DEC is an empowerment investment trust established to engage in business ventures in the context of Broad Based Black Economic Empowerment.
2002 to date	<i>African Decade of PWDs</i> – a continental body sanctioned by the African Union to provide guidance to member States and Governments in achieving the goal of the Decade – full participation, equality and empowerment of PWDs in Africa.
2003 to date	1. <i>The Centre for Alternative and Augmentative Communication</i> – works with people with severe communication disabilities. 2. <i>Rehabilitation International</i> – promotes the rights and inclusion of PWDs; the rehabilitation and the equalisation of opportunities within society for PWDs and their families throughout the world by serving as a medium for deliberation; for exchange of ideas; knowledge, skills and experiences and for compilation and dissemination of information.
2006 to date	<i>The FirstRand Foundation (RMB)</i> – supports non-profit organisations and institutions working towards the development and empowerment of the broader community. Areas of focus include education, job creation, and skills development. The FirstRand Foundation provides for continued social giving for the group
2007 to date	<i>The Thabo Mbeki Development Trust for PWDs (TMDT)</i> – has a mandate to enhance the quality of life of PWDs and promote their integration into mainstream society by supporting their empowerment of through full participation and also by creating partnerships with key stakeholders and strategic partners.

In my working life, I have travelled extensively. I have had the privilege of experiencing the growth and development of the disability agenda in all facets of life. As a disability activist, I value the logo *Nothing About Us without Us*. You cannot understand the situation of a PWD unless you have a disability. As the old adage goes, it is the wearer of the shoe who knows where it pinches most.

Divuseni: A Case Study

The following is a case study of *Divuseni*, a company of women with disabilities.

What is Divuseni?

Divuseni is a Venda¹ word meaning ‘Lift Yourselves Up’. The company was founded by women with disabilities who had already achieved success in their respective careers. Many have served as directors, non-executive directors, trustees or board members on boards of several companies among them Telkom Foundation, RMIB Foundation, Eskom Board and African Access.

So, besides their recognised success, they are all physically disabled. Like all other business women, they have taken up the challenge put across to stand up, take responsibility and play a meaningful role in development.

Their purpose is to ensure women’s entrepreneurship is fostered in South Africa. They also aim at being a key instrument in enabling women to access resources for capacity building. They are determined to empower women in business and commercial so as to contribute towards the realisation of gender equality in the economy. Even though, their focus extends beyond the gender and women interests. Their aim is to realise equality for PWDs. This is achieved through audits, consulting, creating awareness, educating, mentoring, peer counselling, research, sensitisation and training.

¹Venda, also known as Tshivenda, or Luvenda, is a Bantu language and one of the official languages of South Africa.

Vision and Mission

The vision of *Divuseni* is to have a South African society where there are opportunities for all, regardless of race, gender, disability or creed. It advocates an economic dispensation where there is equitable redistribution of wealth and a complete eradication of the imbalances created by the past. *Divuseni* understands the social and economic challenges that face South Africa, in particular disadvantaged groups. Therefore, it is committed to contributing to the promotion and development of national transformation projects to attain the goals enshrined in the RDP.

Through *Divuseni*, members aim at demystifying the stereotype that women with disabilities are limited and cannot perform simple trades like sewing and making handicrafts. Much as these trades are productive, they also serve to perpetuate stereotypes. Given an opportunity, women with disabilities can work and create wealth, just like anyone else.

Types of Business

Divuseni has two core areas of business: instilling and promoting the processes of economic empowerment, and understanding disability and promotion of disability as a human rights.

Divuseni provides a consultation service to other companies on the implementation of economic empowerment measures for optimal productivity. The emphasis as stated is on empowering women and PWDs. Skills transfer to clients and capacity building are the underlying factors in its operational programmes.

There are instances where organisations experience difficulties in adequately accommodating and integrating employees who are disabled in the workplace. In such cases, *Divuseni* provides consultancy services. Emphasis is placed on countering discrimination – whether consciously or unconscious. This area is much broader and involves research and evaluation of empowerment projects.

Projects

Divuseni helps institutions understand disability through skills training, conducting research and disability audits, education, awareness creation and sensitisation. It also organises conferences and manages events that empower young women with disabilities to develop confidence in themselves and in their abilities.

Divuseni plans to expand and reach many other women with disabilities and lift them out of the poverty zone. Through hard work and dedication, PWDs can also enjoy the resources of South Africa. Members have put in place mechanisms to share their experiences both at local and national levels. Collectively, they have established a network of women with disabilities who greatly benefit from the work of *Divuseni*. The growing capacity of *Divuseni* makes it possible to continue to provide sustainable solutions to women with disabilities.

What Makes Divuseni Tick?

Each one of those involved in *Divuseni* understands exactly what disability is and what its implications are. This, together with their wide range of experience and their skills, makes the women of *Divuseni* eminently qualified to fulfil the core functions of the group.

Divuseni is poised to take the business world to another level. It understands the role PWDs can play as strategic partners in development. They are actively seeking out business partners that will enable them to realise their dream of actively contributing to the development of South Africa.

Divuseni acknowledges the fact that there is no separate world of PWDs, let alone one of women with disabilities. Therefore *Divuseni* strongly believes in strategic partnerships with mainstream women who are willing to work with them as business partners – not recipients of charity. *Divuseni* further believes that strategic partnerships should include other sectors of society that are committed to the empowerment of women with disabilities in a meaningful and sustainable manner.

The Women Behind Divuseni

The professional achievements of ‘the women of *Divuseni*’ has already been alluded to. Collectively they have academic qualifications in commerce, financial management, business leadership, biometrics, communications and social sciences. They are highly experienced in their domains and offer consultancy in the following fields:

- New business development
- Conducting disability audits
- Research
- Equity planning and implementation
- Marketing
- Creating awareness and sensitisation on disability
- Education and training
- Conference organisation and events management
- Accounting, auditing and financial planning
- Contract and project management
- Budget forecasts and business planning

A profile of four of the members; Sebenzile Matsebula, Masingita Masunga, Matshidiso Seboni and Manthipi Molamu, is worth examining.

Sebenzile Matsebula

Together with other women with disabilities, Sebenzile started *Divuseni*. She is inspired by broad-based women’s investment companies whose mission is to ensure economic advancement for women by promoting constructive business partnerships. These entities do not include women with disabilities. So, *Divuseni* decided to include them to ensure that women with disabilities also play a meaningful role in investment for sustainable development. She is happy to be part of a group that leads in putting business development at the fore front of their careers.

She has served as a Director in the Office on the Status of PWDs in the Presidency advising the principals. She continues to

participate in international forums that address issues of development from an African and international perspective. They include an address at a forum of the Prime Minister of Denmark with the head of the African Union and African cabinet ministers. She also advises many United Nations agencies on disability issues.

Masingita Masunga

Masingita Masunga represents Swahombe² in Divuseni. Swahombe has a total of 30 young women with disabilities who are share-holders in *Divuseni*. This group of young disabled women with great potential was selected from the participants of the young women's development programme that is run by Masingita, which culminates in an annual event to select the best talent among young women with disabilities in the country. It constitutes of young women with disabilities from all nine provinces of South Africa.

She is passionate about the empowerment of young women with disabilities. Whilst Masingita was struggling to complete her high school she decided to make a difference in the lives of PWDs. In 1998 she began to create projects to uplift and empower PWDs and it was only that year that she passed her school leaving certificate. In 1999 she founded *Miss Confidence South Africa*, the first national beauty pageant for women with disabilities. She was selected a founding member of national youth power against HIV & Aids. In 2000 she got PWDs to act on a scene of Soul City for the first time on South African TV.

In 2001 Masingita started working on motivating people in the community. In 2002 she worked as a producer and researcher for community radio stations around the country. In 2004 she launched Nyeleti³ a music talent search competition for PWDs. Masingita is

²Swahombe Dramatic Ensemble is a performing arts company based in Polokwane. Read more: <http://www.joburg.org.za/content/view/3643/193/#ixzz0jvzoCnkh>.

³Nyeleti Consulting is a firm of consulting engineers which was formed on 1 August 1999. The word Nyeleti, meaning star, symbolises the aspiration of the firm to deliver excellent service to its clients.

the Managing Director of Tinyungubyiseni Talent Promotion Company. She has won the following nominations and awards:

- Shoprite/checkers woman of the year 2004 for the Arts and Culture category
- She was named one of the top ten women in South Africa for 2004 by the Star newspaper.
- Winner of the Amstel Salute to Success 2005.
- Diva award 2005
- Nominee for Cosmopolitan Mover of the year 2005
- One of the cosmopolitan awesome women for 2006
- The Rapport/City Press prestigious Woman 2007.

Matshidiso Seboni

Matshidiso Seboni is a member of the committee of the South African Agency for Science & Technology Advancement (SAASTA). Her responsibilities include the implementation of the HIV & AIDS policy as set out by the organisation and representing disability concerns in the work place. Matshidiso has expansive experience and expertise in the finance sector. She is a self-driven woman who believes that nothing is impossible for a woman with a disability if she puts her mind to achieving something.

Manthipi Molamu

Manthipi Molamu has a driven passion to ensure that PWDs are enabled to contribute meaningfully to the development of South Africa and thereby create a better life for all. Her working experience spans from working as a medical social worker at a provincial hospital (1992-1998), to serving as a Deputy Manager in the Office of the Premier in the North West province in the Office on the Status of PWDs (1999-2003) co-coordinating disability in and around the province, to serving as a Director, heading the Disability unit, at the

national Department of Social Development, co-coordinating the disability programme nationally within the nine provincial departments of social development.

Her job responsibilities were all centred on disability issues, and focused on providing strategic leadership to mainstream disability through integration, and to ensure that the principles of the equalisation of opportunities for PWDs were realised. She led and facilitated a process towards the development of a national policy on disability within the social development context, to enhance development of partnerships and effective service delivery. She further developed the policy implementation strategies and programme that are aligned to departmental mandates, to further define departmental policy on disability.

Manthipi has been strategic in the development of the transformation strategy on protective workshops for PWDs (2005-2007) aimed at implementing an integrated socio-economic empowerment and promotion of rights of PWDs. She has represented the department at a number of international conferences and congresses on disability and was also nominated to attend the nation training on Disability and development in Sweden.

Conclusion

This chapter has discussed the situation of PWDs in South Africa. *Divuseni* has been given as a case study which shows how members are driven by a passion to empower many women with disabilities. From the opportunities that South Africa now provides for PWDs, the women of *Divuseni* can also fully realise their dreams through hard work, dedication and support from strategic partners!

Appendix

St. Paul's University

TPS 402 Disability and Theology

Syllabus

Learning Outcomes

By the end of this course, the student should be able to

- (a) Critically analyse existing traditional values, prejudices, considerations and practices towards a reconstruction of the socio-cultural construction of disability issues and formulate appropriate theological, pastoral and practical responses.
- (b) Explore and integrate theological, practical and pastoral issues with special reference to disability concerns and directly engage in active advocacy actions in their community (addressing legal, ethical, human rights, spiritual issues, etc.).
- (c) Engage in critical reflection on congregational issues through Bible studies, accessibility assessment, liturgical worship, sermons, training and advocacy for leadership and full inclusion of persons with disability.
- (d) Critically assess the traditional understanding of God and particularly explore what it means to be in the image and likeness of God and yet having a disability.

Orientation

1. Introduction and overview of course – course outline, etc.

A Theological Perspective

2. Claiming and Developing a Disability Hermeneutic Towards a Liberating Theology of Disability
3. Doctrines of Creation, Perfection, Imago Dei
4. Theodicy/Sin/Suffering
5. Miracle/Healing/Wholeness
6. Belonging and the Body of Christ
Members of the family of God – place, gifts, roles

A Historical/Sociological Perspective

7. Multicultural perspective and History of Disability
Society's responses to disability

A Psychological Perspective

8. Psychological Implications for Parents, Family, Professionals, Society
Psychology of the Disabled Person

Pastoral and Ministerial Considerations

9. Leadership for Inclusiveness, Obstacles to Inclusiveness
10. Worship – accommodations, modifications, accessibility assessment – implications for preaching and Bible studies
11. Pastoral Care and Counselling

Church and Public Policy Considerations

12. Church and Advocacy

Human Rights – theory and practice, advocacy, self-advocacy
Involvement of the State

13. International Obligations – UN Standard Rules, Convention, etc.

Disability and Public Issues – health, poverty, education, gender, unemployment, security, etc.

14. Action for Empowerment – policy, technology, services, resources

Prevention, Early Identification, Intervention.

Disability, Society, and Theology

Bibliography

- Abraham, K.C. "Theological Education and Disability" in *Disability Discourse for Theological Institution* ed by Wati Longchar (Jorhat: ETE-WCC/CCA, 2006), 14.
- Abrams, Judith. *Judaism and Disability: Portrayals in Ancient Text from the Tanach through the Bavli*. Washington, D.C.: Gallaudet University Press, 2000.
- Albert, Bill and Miller, Carol, (2005) *Mainstreaming disability in development: Lessons from Gender Mainstreaming*, Disability KAR, available at <http://www.disabilitykar.net/resources/karprogreports.html>
- Alex Ndezi: The Disability Movement in Uganda 1999.
- Allen Stuart "What is work for? The right to Work and the Right to be idle" In Brown R.K (ed) *The Changing Shape of Work*, Macmillan UK, 1997.
- Alston J (1966) The Jerusalem Bible.
- Anderson, Robert C. "In Search of the Disabled Human Body in Theological Education: Critical Perspectives on the Construction of Normalcy—An Overview." In Robert C. Anderson, ed. *Graduate Theological Education and the Human Experience of Disability*. Binghamton, NY: The Haworth Pastoral Press, 2003.
- Anderson, P. and Kitchin, R.(2000) Disability, space and sexuality: access to family planning services *Social Science and Medicine* 51 (11): 1163-1173.
- Aquinas, Thomas. *Summa Theologia*, ed. by the English Dominican Fathers. Burns, Pates and Washbourne, Ltd., 1922.
- Armstrong, Felicity and Lee Barton, *Disability, Human Rights and Education: Cross-Cultural Perspectives*. Buckingham, Philadelphia: Open University Press, 1999.

- Avalos, H.; Melcher, S. J. and Schipper, J. *This Abled Body: Rethinking Disabilities and Biblical Studies*. Atlanta: Society of Biblical Literature, 2007.
- Bankole, A., Singh, S., Woog, V. & Wulf, D. Risk and protection: youth and HIV/Aids in sub-Saharan Africa (New York, Alan Guttmacher Institute), 2004.
- Barnes, C. *Disabled People in Britain and Discrimination*. London: Hurst and Company (in Association with the British Council of Organisations of Disabled People) and Development (GPDD) Power point presentation May 20-21 2004 [HYPERLINK](#), 1991.
- Barton, Len, *Disability and Society: Emerging Issues and Insights*. London and New York: Longman, 1996
- Barton, Len and Mike Oliver, *Disability Studies: Past, Present and Future*. Leeds: The Disability Press, 1997.
- Baylies, Carolyne. 'Disability and Development.' Lecture Notes, University of Leeds. Politics of Schooling. Hutchinson, London, 2002.
- Becker, J.; Lopez, O.; Dew, M. & Aizenstein, H. (2004) Prevalence of cognitive disorders differs as a function of age in HIV virus infection AIDS 18 (Suppl 1): 11-18.
- Benton, Janice LaLonde & Mary Jane Owen. *Opening Doors to People with Disabilities, Vol. I: Pastoral Manual and Vol. II: The Resource File*. Washington, DC: National Catholic Office for Persons with Disabilities, 1997.
- Bible: The New Open Bible, New American Standard Bible* Nashville: Thomas Nelson Inc., 1990
- Black, Cathy A. *A Healing Homiletic: Preaching and Disability*. Nashville, TN: Abingdon Press, 1996.
- Black, Kathy. *A Healing Homiletic: Preaching and Disability*. Nashville, Tennessee: Abingdon Press, 1996.
- Blair, Maud, Janet Holland and Sue Sheldon, *Identity and Diversity: Gender and the Experience of Education*. Clevedon, UK: Multilingual Matters Ltd., 1995.
- Blair, W. Daniel. "Christian Theology and Human Disability: A Literature Review." In Robert C. Anderson, ed. *Graduate Theological Education and the Human Experience of Disability*. Binghamton, NY: The Haworth Pastoral Press, 2003.

- Block, Jennie Weiss. *Copious Hosting: A Theology of Access for People with Disabilities*. New York: The Continuum International Publishing Group, 2002.
- Bonnel R (2004) Poverty Reduction Strategies and Disability Global Partnership on Disability <http://www.worldbank.org/disability>.
- Byrne, Eileen. 'Education for Equality', in Arnot, M. and Weiner G. (eds). Gender and the Environments, edited by John Swain, Sally French, Colin Barnes and Carol Thomas, Published in Bonney, Selina. "Disabled people, disability and sexuality." In Disabling Barriers - Enabling association with The Open University, 2nd edition. London: Sage Publication, 2004: 125. Plus News, Dar-es-Salaam, 1987.
- Campbell, John. *Being Biblical*. London: United Reformed Church, 2003.
- Chappell, P. & Johannsmeier, C. The impact of CBR as implemented by Community Rehabilitation Facilitators on PWDs, their families and communities in South Africa. Unpublished, CREATE, 2007.
- Chenu, D. M, *Towards Understanding St. Thomas*, trans. A.M. Landry and D. Huglus. Chicago: Henry Regnery, 1964
- Chuang H. T. & Atkinson M. (1996) AIDS knowledge and high-risk behaviour in the chronic mentally ill. *Canadian Journal of Psychiatry*; 41(5): 269-72.
- Cilson, Etienne *The Christian Philosophy of St. Thomas Aquinas*, trans. L.K. Shook. New York: Random House, 1956.
- Coleridge, Peter, *Disability, Liberation and Development*. UK and Ireland: Oxfam, 1993.
- Coleridge, Peter. *Disability, Liberation and Development* Oxfam, Oxford, UK, 1993.
- Coleridge, Peter. Paper presented during the Leonard Cheshire International Conference on Inclusive Development, Bangkok, Thailand, 2005.
- Collins, P., Geller, P., Miller, S., Toro, P. & Susser, E. (2001). Ourselves our bodies, our realities: an HIV prevention intervention for women with severe mental illness. *Journal of Urban Health*, 78 (1): 162-175.
- Cooper, Burton. 1992. "The Disabled God." *Theology Today*. Vol. 49, No. 2.
- Corker, Mairan & Sally French (eds.). *Disability Discourse*. Buckingham, Philadelphia: The Open University Press, 1999.
- Coulter, David L. & William C. Gaventa, ed. *Journal of Religion, Disability and Health. Quarterly Journal*. Binghamton, New York: The Haworth Pastoral Press.

- Coulter, David and William C. Gaventa, ed. *The Theological Voice of Wolf Wolfensberger*. Binghamton, NY: The Haworth Pastoral Press, 2001.
- Creamer, Deborah. 1995. "Finding God in Our Bodies: Theology from the Perspective of People with Disabilities." In *Journal of Religion in Disability and Rehabilitation*. Vol. 2 (1).
- "Toward a Theology that Includes the Human Experience of Disability." In Robert C. Anderson, ed. *Graduate Theological Education and the Human Experience of Disability*. Binghamton, NY: The Haworth Pastoral Press, 2003.
- Cunningham, David and Janet, *Adventures unlimited*, 1982. (a program designed for 11yr old children).
- Davie, Ann Rose & Ginny Thornburgh. *That All May Worship: An Interfaith Welcome to People with Disabilities*. Washington, DC: National Organisation on Disability, 2000.
- Derksen J (1975) Self help Organisations and Independent Living.
- Duncan, Joan, and Laura Arntson, *Children in crisis: Good practices in evaluating psychosocial programming*:http://www.savethechildren.org/publications/technical-resources/emergencies-protection/Good_Practices_in_Evaluating_Psychosocial_Programming.pdf
- Eareckson Tada, Joni. *When Is It Right to Die: Suicide, Euthanasia, Suffering, Mercy*. Grand Rapids: Zondervan Publishing House, 1992.
- Eisland, Nancy L., *The Disabled God, Toward a Liberation Theology of Disability*. Abingon Press, Nashville.
- "Encountering the Disabled God." *The Bible in Transmission* (Spring) 2004.
- & Donald E. Saliers. *Human Disability and the Service of God: Reassessing Religious Practice*. Nashville, Tennessee: Abingdon Press, 1998.
- Elshout, E., Wilhelm, Fontaine, C., Eiesland, N., Stiteler, McCollum and Wenig, M.M. (1994: 99-134). Women with Disabilities; A Challenge to Feminist Theology. A Roundtable Discussion in *Journal of Feminist Studies in Religion*, vol. 10.
- Elwan, A. Poverty and disability. A review of the literature. Discussion. Paper No. 9932, World Bank, 1999.
- Epperly, Bruce G. *God's Touch: Faith, Wholeness and the Healing Miracles of Jesus*. Louisville, Kentucky: Westminster John Knox Press, 2001.

- Erevelles, Nirmala.. "Bodies That Do Not Matter: Social Policy, Education, and the Politics of Difference." Doctoral Dissertation. Syracuse University, 1998.
- Erikson, Erik H., *Childhood and Society*. New York: W. W. Norton & Company, 1963.
- Francis, D. and Rimmensberger, N. (2005) Selling HIV/Aids: a case of mixed messages *Acta Academica* 37(3): 88-107.
- Fenichel, Otto, *The Psychoanalytic Theories of Neurosis*. New York: W. W. Norton & Company, 1945.
- Finkelstein, V. *Attitudes and Disabled People*. Geneva, World Health Organization, 1980.
- Finkelstein, Vic. (1980) *Attitudes and Disabled People: Issues of Discussion* World Rehabilitation Fund.
- Freire P. (1975) *Pedagogy of the Oppressed*.
- Freud, Anna, *The Ego and the Mechanism of Defense*. New York: International Universal Press, 1966.
- Freud, Sigmund, *Introductory Lectures on Psycho-Analysis*. New York: W. W. Norton & Company, 1966.
-, *A General Introduction to Psychoanalysis*. New York: Liveright Publ., 1920.
- Fritzon Arne and Samuel Kabue. *Interpreting Disability: A Church of All and For All*. WCC Publication, Geneva, 2004.
- Fritzon, Arne. 2004. "Disability and Meaning." In Arne Fritzon and Samuel Kabue, *Interpreting Disability: A Church of All and for All*. Geneva: WCC Publications.
- Foucault, Michel. *The History of Sexuality, Vol. I, An Introduction*. New York: Pantheon Books, 1978.
- Gabbard, Glen O., *Psychodynamic Psychiatry in Clinical Practice*. Arlington: American Psychiatric Publishing, Inc., 1994.
- Garland, R. R. J. *The Eye of the Beholder: Deformity and Disability in the Graeco-Roman World* London, Duckworth, 1995.
- Gaventa, Bill, ed. *Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and their Families*. New Brunswick, New Jersey: The Boggs Centre-UAP, 2002.
- Gichanga Emmy, *Basic Counseling and skills*, 1999.
- Gilligan, Carol, *In a Different Voice*. Cambridge, MA: Harvard University Press, 1982.

- Govig, Stewart D. *Souls are Made of Endurance: Surviving Mental Illness in the Family*. Louisville, Kentucky: Westminster John Knox Press, 1994.
- Govig, Stuart D. *In the Shadow of Our Steeples: Pastoral Presence for Families Coping with Mental Illness*. New York and London: The Haworth Pastoral Press, 1999.
- Gower, Ralph, 1987 *The New Manners of Customs of Bible times*. Scripture Press, England.
- Groce, N. (2004) Capturing hidden voices: Global survey on HIV/Aids and disability. Accessed from <http://globalsurvey.med.yale.edu>
- Groce, N. E. and Trasi, R. (2004) Rape of individuals with disability: AIDS and the folk belief of virgin cleansing *The Lancet* 363: 1663-1664
- Groce, N. (2005) HIV/Aids and individuals with disability *Health and Human Rights* 8 (2): 215-224.
- Groce, N.; Yousafzai, A. & Van Der Maas, F. HIV/Aids and Disability: Differences in HIV/Aids Knowledge between Deaf and Hearing Population, Nigeria, 2005.
- Groce, N.; Trasi, R. & Yousafzai, A. (2006) Guidelines for Inclusion of Individuals with Disability in HIV/Aids Outreach Efforts. Accessed from <http://globalsurvey.med.yale.edu>
- Haraway, Donna J. *Simians, Cyborgs, and Women: The Reinvention of Nature*. New York: Routledge, 1991.
- Hamilton, Victor, P. "The Book of Genesis 18-50" *The New International Commentary of the Old Testament*. William B. Eerdmans Publishing Company, Grand Rapids, Michigan, 1979.
- Hanass-Hancock, J. The notion of disability in the Context of HIV/Aids in KwaZulu-Natal, South Africa. Unpublished Doctorate thesis. University of Berlin, Germany, 2008.
- Harris et al (2003) Disability, Equality and human Rights.
- Helander E. (1999) Prejudice and Dignity: an introduction to Community-Based Rehabilitation, UNDP
- Henry M (1965) Commentary on the whole Bible in one volume.
- Heumann, Judith. (2005) "Inclusive Education" World Bank <http://www.worldbank.org/civilsocietyengagementnewsletter>
- Hobbs, T. R. "2Kings". *Word Biblical Commentary*. Word Books Publishers, Waco, Texas, 1985.

- Horwath, J; Lees, J, Sidebotham, J; Higgins, J and Imitiaz A ‘*Religious parents want* Joseph Rowntree Foundation. Available at www.jrf.org.uk Summer 2008. Foundation, USA, 2008.
- Hunter, Rodney J., ed. *Dictionary of Pastoral Care and Counseling*, Nashville: Abingdon Press, 1990.
- Ikenye, Ndung’u J.B., *African Christian Counseling*. Nairobi: Envoy Graphic & Print Systems, 2002.
-, *Decolonization of the Kenyan Soul*. Nairobi: Envoy Graphic & Print Systems, 2002.
- Ingstadt, B. (1990) The Cultural Construction of AIDS and Its Consequences for Prevention in Botswana. *Medical Anthropology Quarterly*, 4(1): 28-40.
- Isherwood, L. & E. Stuart. *Introducing Body Theology*. Sheffield, England: Sheffield Academic Press, 1998.
- Karp, Gary “*Early history of disability*” available at www.lifeonwheels.net/writings/history.html
- Kisanji J. (1995) Growing up Disabled: Disabled children in Developing Countries in Mandela N. (1995) *A Long Walk to Freedom*
- Lau, R.; Goh, B.; Estreich, S.; Cox, S. and Levy, I. (1990) Adult gonococcal keratoconjunctivitis with AIDS *British Journal of Ophthalmology* 74: 52.
- Leclerc-Madlala, S. (1999) Demonising woman in the era of AIDS: on the relationship between cultural construction of both HIV/Aids and femininity. *Society in transaction*, 32(1): 39-46.
- Lees, J. A. Interpreting the bible with people with communication difficulties. Unpublished MTh Thesis, Department of Theology, University of Natal, South Africa, 1997.
- Liberation through ‘Liberator’: A study of conversation. Paper presented at the European Academy of Child Disability, Lisbon, Portugal, 1998.
- Remembering the bible as a ‘critical pedagogy of the oppressed’. In G O West (ed) *Reading Other-wise: Socially Engaged Biblical Scholars Reading with their Local Communities*. Atlanta: Society of Biblical Literature, 2007a.
- *Word of Mouth: using the remembered bible for building community*. Glasgow: Wild Goose, 2007b.
- Enabling the Body. In H Avalos, S J Melcher, and J Schipper, (eds) *This Abled Body: Rethinking Disabilities and Biblical Studies*. Atlanta: Society of Biblical Literature, 2007c.

- Leone, Lu with Ginny Thornburgh. "Each Made in God's Image, Each a Unit of God's Grace." In Robert C. Anderson, ed. *Graduate Theological Education and the Human Experience of Disability*. Binghamton, NY: The Haworth Pastoral Press, 2003.
- Levinson, Daniel J., *The Season's of a Man's Life*, New York: Ballantine Books, 1978.
- Link, B. & Phelan, J. (2001). Conceptualising stigma. *Annual Review of Sociology*, 27 pp. 363-385.
- Longchar, Wati and Gordon Cowans. ed, by *Disabled God Amidst Broken People: Doing Theology from Disability Perspective*. Manila: ATESEA, 2007.
- ed. by *Disability Discourse for Theological Institution* ed by Wati Longchar. Jorhat: ETE-WCC/CCA, 2006.
- Macha, Elly. 'Access to education: from primary to tertiary'. Paper presented at the Leonard Cheshire Disability conference on the UN Convention on the Rights of PWDs in Addis Ababa, Ethiopia, 2008.
- Mandela N. (1995) A Long Walk to Freedom.
- Mbiti J. (1965) African religions and Philosophy, Heinemann; London: 1970.
- (1965) African religions and Philosophy Possibility of Independent Living in Africa—Available at <http://www.independentliving.org/toolforpower/tools5.htm>
- McWilliams, Nancy, *Psychoanalytic Diagnosis: Understanding Personality Structure in Clinical Process*, New York: Guilford Publications, 1994.
- Meier, Paul D., *Introduction to Psychology and Counseling: Christian Perspectives and Applications*, Grand Rapids, Michigan: Baker Publishing Group, 1991.
- Miles, Susan. "Creating conversations: The evolution of the Enabling Education Network" In Stone, E "Disability and Development" The Disability Press, UK, 1999.
- "Inclusive Education" In Barron T and Amarena P Eds *Disability and Inclusive Development* Leonard Cheshire International UK, 2007.
- Miller, Patricia H., *Theories of Developmental Psychology*, New York: W. H. Freeman & Co Ltd., 1993.
- Milligan, M. and Neufeldt, A. (2001) The myth of asexuality: A survey of social and empirical evidence *Sexuality and Disability* 19(2): 91-109.

- Moltman-Wendel, Elizabeth. *I Am My Body: A Theology of Embodiment*. New York: The Continuum Publishing Company, 1994.
- More, Burness E. and Bernard D. Fine, Eds., *Psychoanalytic Terms and Concepts*, New Haven & London: Yale University Press, 1990.
- Morris, Jane. *Encounters with strangers: Feminism and Disability*, Women's Press, 1996.
- Mulindwa, I. (2003) Study on Reproductive Health and HIV/Aids among PWDs in Kampala, Katakwi and Rakai Districts (Kampala, Uganda: Disabled Women's Network and Resource Organisation).
- Nasasimhan, M. C., Mukherjee A. K. *Disability A Continuing Challenge*. Wiley Eastern Limited, New Delhi, 1990. Ndurumo, M. (1993) *Exceptional Children*
- Nelson, James B. *Body Theology*. Louisville: Westminster/John Knox Press, 1992.
- Newman, Gene & Joni Eareckson Tada. *All God's Children: Ministry with Disabled Persons*. Grand Rapids: Zondervan Publishing House, 1981.
- Nganwa, A.; Batesaki, B., Balaba, A.; Serunkuma, P. & Yousafzai, A. HIV/Aids and Community Based Rehabilitation (CBR) development In Hartley, S. (Ed.). *CBR: A participatory strategy in Africa* London: University College London, Centre for International Child Health, 2002.
- Nolan, Albert. *Jesus Before Christianity*. Maryknoll, New York: Orbis Books, 1976.
- Nouwen, Henri J.M. *Adam: God's Beloved*. Maryknoll, New York: Orbis Books, 1997.
- *The Wounded Healer*. New York, New York: Image Books, Doubleday, 1972.
- Nussbaum, Marta C. and Jonathan Glover, *Women, Culture and Development*, Oxford: Clarendon Press, 1995.
- Oliver, M. Re-defining disability: a challenge to research. In J. Swain, V. Finkelstein, S. French and M. Oliver (eds.) *Disabling Barriers - enabling environments*. London: Sage Publications, 1993.
- Oliver Mark. *Understanding Disability, from Theory to Practice* Palgrave, UK, 1996.
- Oliver, Michael, *Understanding Disability: From Theory to Practice*, London: MacMillan Press Ltd., 1996.

- Parker, W. and Birdsall, K. (2005) HIV/Aids, stigma and faith based organisations: a review Centre for AIDS Development, Research and Evaluation (CADRE).
- Pettifor, A. HIV and Sexual Behaviour among Young South Africans: A National Survey of 15-24 year olds. Reproductive Health Research Unit (RHU), South Africa, 2004.
- Pierson, Jim. *Exceptional Teaching: A Comprehensive Guide for Including Students with Disabilities*. Cincinnati, Ohio: Standard Publishing, 2002.
- Philander, J. and Swartz, L. (2006) Needs, barriers and concerns regarding HIV prevention among South Africans with visual impairments: A key informant study Journal of Visual Impairment & Blindness February: 111-115.
- Pillay, M. (2003) Church discourse on HIV/Aids: A responsible response to a disaster Scriptura 82: 108-121.
- Phillips, Bob, *What to do until the Psychiatrist comes*, Eugene, Oregon: Harvest House Publishers, 1995.
- Philpott, G. *Jesus is Tricky and God is Undemocratic: the kingdom of God in Amawoti..* Pietermaritzburg: Cluster Publications, 1993.
- Poling, James N. and Donald E. Miller, *Foundations for a Practical Theology of Ministry*, Nashville: Abingdon Press, 2000.
- Possibility of Independent Living in Africa—Available at http://w.w.w.independentliving.org/tool_forpower/tools5.hrr
- Prokes, Mary Timothy. *Towards a Theology of the Body*. Grand Rapids: William B. Eerdmans Publishing Company, 1996.
- Rapuro, O. On the subject of disability *Baobab* 27 Arid Lands Information Network (ALIN) Dakar, 1998.
- Reeves, Kathy N., *Accessibility Audit for Churches: A United Methodist Resource Book About Accessibility*. New York: General Board of Global Ministries. The United Methodist Church, 1994.
- Robertson, P.; Bhate, S. and Bhate, M. (1991) AIDS: education and adults with a mental handicap. Journal of Mental Defect Research 35: 475-480.
- Rogers, E. F. *Sexuality and the Christian Body: Their Way into the Triune God*. Oxford, England: Blackwell Publishers, 1999.
- R.P. Callet Ny tantaran'ny Andriana.

- Salome Wairimu Muigai is a Consultant on Gender and has a lot of interest in the disability Handicap International, 2007 Guide pour une approche globale du handicap.
- Santrock, J.W., *Adolescence*, 10th ed., Madison, Wisconsin: Brown & Benchmark Publishers, 2005.
- Shakespeare, Tom et al. *The Sexual Politics of Disability*. London & New York: Continuum International Publishing, 1996.
- (2000) Disabled sexuality: Towards rights and recognition *Sexuality and Disability* 18(3): 159-166.
-; Gillespie-Sellis, K. & Davies, D. *The Sexual Politics of Disability* London: Cassell, 1996.
- Shapiro, Joseph P. *No Pity: People with Disabilities Forging A New Civil Rights Movement*. New York: Random House Inc., 1993.
- Siberschmidt, M. (2003) Male sexuality in the context of socio-economic change in rural and urban east Africa *Sexuality in Africa Magazine*: 5-7.
- Smith, E.; Murray, S. F. & Kaseba, C. (2004) Barriers to accessing Safe Motherhood and reproductive health services: the situation of women with disabilities in Lusaka, Zambia. *Disability and Rehabilitation* 26: 121-127.
- Spencer, Michael: "*The Christian and Mental Illness: the Church and the Mentally Ill*" – <http://www.internetmonk.com/archive/the-christian-and-mental-illness-v-the-church-and-mental-illness>
- Sprick, K. (2005) HIV/Aids and disability CBR Update 2(1): 1-2.
- Stone, Emma. *A Complicated Struggle: Disability, Survival and Social Change in the Majority World*. In Priestly, M. (ed.) *Disability and the Life Course: Global Perspectives*. Cambridge University Press, 2001.
- Sullivan, G.; Koegel, P.; Kanouse, DE.; Cournos, F.; McKinnon, K.; Young, AS. & Bean, D. (1999) HIV and people with serious mental illness: The public sector's role in reducing HIV risk and improving care. *Psychiatric Services* 50: 648-652.
- Sweeny, J. Double Exposure: Disability and HIV/Aids in sub-Saharan Africa. Unpublished Masters Thesis. University of Manchester, England, 2004.
- Swartz, L.; Schneider, M. and Rohleder, P. HIV/Aids and disability: new challenges. In *Disability and social change: a South African agenda* (edited by Watermeyer, B. et al.) HSRC, Cape Town, 2006.

- Tataryn, M. (2005) Bridging the gap: a call for cooperation between HIV/ Aids activists and the global disability movement Accessed from <http://v1.dpi.org/lang-en/resources/details.php?page=325>
- Thatcher, Adrian. "The Virus and the Bible-How Living with HIV helps the Church to read it" a paper presented at workshop on "Ethics on HIV & AIDS Prevention" at on 8th January, 2008 at Johannesburg.
- Thornburgh, Ginny, ed. *Loving Justice: The ADA and the Religious Community*. Washington, DC: National Organisation on Disability, 1999.
- Toensing, H. J. (2007) "Living among the tombs". Society, mental illness and self-destruction in Mark 5:1-20. In H Avalos, S J Melcher, and J Schipper, (eds) *This Abled Body: Rethinking Disabilities and Biblical Studies*. Atlanta: Society of Biblical Literature.
- Tomkins, S. S., *The Positive Affects*, Volume 1, New York: Springer 1962.
....., *The Negative Affects*, Volume 2, New York: Springer 1963
- Tyson, Phyllis and Robert L. Tyson, *Psychoanalytic Theories of Development*, New Haven and London: Yale University Press, 1990.
- Ustun, T. Bedirhan and Others, *Disability and Culture: Universalism and Diversity*, Seattle: Hogrefe and Huber Publishers, 2001.
- Vernon, Ayesha. The experience of disabled Black and Minority Ethnic Women. PhD Thesis. University of Leeds, UK, 1998.
- Vanier, Jean. *Community and Growth*. Mahwah, New Jersey: Paulist Press, 1989.
- Walker, Robert L. *Breaking the Sound Barrier in Your Church*. New York, New York: General Board of Global Ministries, The United Methodist Church, 2001.
- Ward, John C. "The Disabled God? How a theological anthropology that embraces human disability changes how we image God." MA dissertation. Murdoch University, 2000.
- Ware, Norma, Kim Hopper, Toni Tugenberg, Barbara Dickey, Daniel Fisher: *Connectedness and Citizenship: Redefining Social Integration*: <http://psychservices.psychiatryonline.org/cgi/content/full/58/4/469>; April 2007; Vol. 58; No. 4 at page 469-474.
- Webb-Mitchell, Brett. *Dancing with Disabilities: Opening the Church to All God's Children*. Cleveland, Ohio: United Church Press, 1996.

- Webb-Mitchell, Brett. *Unexpected Guests at God's Banquet: Welcoming People with Disabilities into the Church*. New York: The Crossroad Publishing Company, 1994.
- *Dancing with Disabilities: Opening the Church to All God's Children*. Cleveland: United Church Press, 1996.
- Wenham, Gordon J. "The Book of Leviticus" *The New International Commentary of the Old Testament*. 1979 William B. Eerdmans Publishing Company, Grand Rapids, Michigan.
- West, Gerald O. Artful facilitation and creating a safe interpretive site: analysis of aspects of a bible study. In H deWit, L Jonker, M Kool and D Schipani (eds) *Through the Eyes of Another: Intercultural Reading of the bible*. Amsterdam: Institute of Mennonite Studies, Vrije Universiteit, 2004.
- West, Gerald O. *The Academy of the Poor: Towards a Dialogical Reading of the Bible*. Sheffield: Sheffield Academic Press, 1999.
- West, Gerald and Ujamaa Centre Staff Doing Contextual bible Study: A Resource Manual. Pitermaritzburg: The Ujamaa Centre for Biblical & Theological Community Development & Research, 2007.
- Whiteside, A., & Sunter, C. AIDS: The challenge for South Africa. Cape Town: Human and Rossouw (Ptv) Ltd and Tafelberg Publishers Ltd, 2000.
- Wilke, Harold H. *Creating the Caring Congregation: Guidelines for Ministering with the Handicapped*. Nashville: Abingdon Press, 1980.
- *Angels on My Shoulders & Muses at My Side*. Nashville: Abingdon Press, 1999.
- "Access to Professional Education." In Robert C. Anderson, ed. *Graduate Theological Education and the Human Experience of Disability*. Binghamton, NY: The Haworth Pastoral Press, 2003.
- Wolfensohn, J. D. (2002) 'Poor, Disabled and Shut Out' Washington Post, 3.12.02 www.globalpolicy.org/soecon/develop/2002/1203 <Accessed 10.7.04>
- Yousafzai, A.; Dlamini, P.; Groce, N. & Wirz, S. (2004) Knowledge, personal risk and experiences of HIV/Aids among PWDs in Swaziland International Journal of Rehabilitation Research 27: 1-5.
- Yousafzai, A. and Edwards, K. (2004) Double the burden: A situation analysis of HIV/Aids and young PWDs in Rwanda and Uganda Save the Children Fund.

Zarb, Gerry (1992: 125-138) On the Road to Damascus: first steps towards changing the relations of disability research production. *Disability, Handicap and Society*, 7 (2).

Zisser, A. and Francis, D. (2006) Youth have a new attitude on AIDS, but are they talking about it? *African Journal of AIDS Research* 5(2):189-196.

Articles

AIDS Action (1997) Disability and HIV/Aids Special Joint Issue with CBR News Issue 35 AHRTAG London.

Analysis. <http://arabstates.undp.org/contents/fileGenderMainstreamingTraining.pdf>

Basic Education Statistics in Tanzania (2007).

Convention on the Rights of Persons with Disabilities (1981).

Citizen Television, May, 2008

Daily Nation, August, 1998

Dept. of Education (2001) Education White Paper 6: Building an inclusive education and training system. South Africa.

Department for International Development (DFID) Disability, Poverty and Development DFID, London, 2000.

Disability advocacy among Religious Organizations: Histories and Reflections, by Albert A. Herzog, Jr. *raduate Theological Education and the Human Experience of Disability* by Robert C. Anderson

Disability and its obstacles in Development- Available at <http://www.google.com/custom?q=Disability+and+its+obst>

Disability and its obstacles in Development- Available at <http://www.google.com/custom?q=Disability+and+its+obst>

Disabled People's Organisations in UN Perspective (2007) 61/106.

«Disability, Poverty and Development» (DFID – UK Department for International Development, February 2000). <http://62.189.42.51/DFIDstage/Pubs/files/disability.pdf>

Disappointing Progress of Disability Rights in Madagascar. By Fela Razafinjato http://www.disabilityworld.org/09-11_04/gov/madagascar2.shtml

Employment and Labour Relations Act (2004).

European Disability Forum (EDF): www.edf-feph.org

FIDA Kenya, IED, KHRC, and The League of Kenya Women Voters, (2002); Safeguarding Women's Gains Under The Draft Constitution

- Government of Uganda: The equal opportunities ACT 2007.
: Constitution of the Republic of Uganda.
: The local Government ACT 1997
: The Local Government ACT 1997 and the
 Local Government (Amendments) ACT 1997
 Hands at Work in Africa (2008) www.handsatwork.org/our-heart/
 <Accessed on 23/4/2008>
 Handicap International, 2007 Guide pour une approche globale du handicap
, 2007 Projet sur « Vers une pleine reconnaissance
 des droits des personnes handicapées.
 Hesperian Foundation. (2007) *Health Handbook for Women with
 Disabilities* Hesperian
[http://retirement.gov/policy/docs/progdsc/ssptw/2008-2009/
 africa/madagascar.html](http://retirement.gov/policy/docs/progdsc/ssptw/2008-2009/africa/madagascar.html)
<http://www.disability.qld.gov.au/stories/kathy-knowles/>
<http://www.religionanddisability.org/>
 ICD (2008) Survey Report on Disability and Educational Rights.
 International Disability Alliance (IDA):
 www.internationaldisabilityalliance.org
 Land Act (1999).
 Lovelife (2004) Report on Activities and Progress Lovelife, South Africa.
 ILO, UNESCO, UNICEF, WHO (2004) Joint Position Paper on
 CBR with and for PWDs. Geneva.
 Macmillan Encyclopedia.
 Madagascar: Disability—Shame, Honor or Reality? By Fela Razafinjato
 (fela.csm@netclub.mg) [http:// www.disabilityworld.org/09-11_04/
 news/madagascar.shtml](http://www.disabilityworld.org/09-11_04/news/madagascar.shtml)
 Ministry of Gender, Labour and Social Development: National Policy on
 Disability.
 Moks RAZAFINDRAMIANDRA, 1994 Angano Malagasy nofohazina
 Société Malgache d'édition
 National Health Policy Education and Training Policy (1995).
 National census Report (2002).
 National Disability Policy (2004).
 NUDIPU: Information and Public Relations strategy 2008-2010, Christine
 Butegwa, Stella Kigozi (Independent Consultants) 2007.
 NUWODU: From stigmatization to Liberalization (2004-2006).

- NUDIPU: The PWDs ACT 2006 simplified version, The International Republication Institute (IRI) 2008.
- ODP Integrated National Disability Strategy for South Africa White Paper, South Africa, 1997.
- Poverty and Human Development (1991).
- Religion and Disability: Essays in Scripture, Theology, and Ethics By Marilyn E. Bishop; Published by Sheed & Ward, 1995
- Report on Matrimonial cases (2006).
- Tanzania Albino Society (2008) Report on the Study Visit to establish motives behind killings of citizens with Albinism in the Northern Part of Tanzania.
- The Ecumenical Response to Disability: The World Council of Churches; by Sam Kabue; Available online on www.haworthpress.inc
- The International Disability and Development Consortium (IDDC): www.iddc.org.uk
- The Persons with Disabilities Act 2003, Government Printers.
- The United Nations Convention on the Rights of Persons with Disabilities
- The Standard Rules on the Equalization of Opportunities for Persons with Disabilities. United Nations, A/RES/48/96, 85th plenary meeting, 20 December 1993
- The United Methodist Church: 'We Act in Society': http://www.umc.org/site/c.lwL4KnN1LtH/b.2294683/k.B1A4/Church_and_Society.htm
Excerpt from *The Book of Resolutions of The United Methodist Church 2008*. The United Methodist Publishing House, 2008.
- UN Convention on the Rights of PWDs, 2006. www.un.org/esa/socdev/enable/rights/convtexte.htm
- UN Documents [1]: Convention on the Rights of Persons with Disabilities <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- UN Documents [2]: Principles for the protection of persons with mental illness and for the improvement of mental health care: <http://www.un-documents.net/pppmi.htm>
- UN Documents [3]: Standard Minimum Rules for the Treatment of Prisoners: <http://www2.ohchr.org/english/law/treatmentprisoners.htm> p3
- UN (1993) Standard Rules on the Equalisation of Opportunities for PWDs UN, New York.
- UNAIDS & WHO (2007) AIDS epidemic update United Nations, Geneva.

- UNDP, (2001); Gender and Development Programme. Learning and information Pack: Gender United States Conference of Catholic Bishops. Washington, DC: *Pastoral Statement, 1978. Guidelines for the Celebration of the Sacraments with Persons with Disabilities, 1995. Welcome and Justice for Persons with Disabilities, 1998.*
- UNICEF (1999) Global survey of adolescents with disability: an overview of young people living with disabilities: their needs and their rights. New York: UNICEF Inter-Divisional Working Group on Young People, Programme Division.
- United Nations Commission on the Status of Women, (1979); The Convention on the Elimination of all Forms of Discrimination against Women. <http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm>
- United Nations Report of the Economic and Social Commission for Asia and Pacific (2006).
- United Republic of Tanzania (2007) Poverty and Human Development
- WHO (2001) International Classification of Functioning Disability and Health (ICF)
- Wikipedia [1]: http://en.wikipedia.org/wiki/Medical_model_of_disability
- Wikipedia [2]: http://en.wikipedia.org/wiki/Social_model_of_disability
- www.ncpd.org: Resource for National Catholic Partnership with Disability
- www.un.org/disabilities Webster's New World Dictionary, 1988.
- Women and Leadership: Transforming Visions and Diverse Voices
USAID Disability Policy Paper (USAID, September 1997)
<http://www.usaid.gov/about/disability/DISABPOL.FIN.html>
- World Bank (2004b) Washington Group on Disability Statistics <http://www.worldbank.org/disability>
- World Bank (2003) Adolescents and Youth with Disabilities: Issues and Challenges Washington, DC: World Bank.
- World Council of Churches (2003) A Church of All and for All: An interim statement Len Barton and Mike Oliver, Editors (1997); Disability Studies: Past Present and Future' Leeds: The Disability Press, WCC, Geneva. *A Church of All and For All: An Interim Theological Statement.* WCC, 2004.
- World Program of Action United Republic of Tanzania (2007).
(1981) World Program of Action
(1991) National Health Policy
(1995) Education and Training Policy

- (1999) Land Act
- (2002) National census Report
- (2004) Employment and Labour Relations Act
- (2004) National Disability Policy
- (2006) Disabled People's Organizations in UN Perspective
- (2006) Report on Matrimonial cases
- (2007) Basic Education Statistics in Tanzania
- (2007) 61/106 Convention on the Rights of Persons with Disabilities

Contributors

Janet Amegatcher

Founding Chairperson of the Pan African Network of Users and Survivors of Psychiatry (PANUSP). She the director for Mind Freedom Ghana, a local NGO fighting for the human rights of persons with psychosocial disabilities

Paul Chappell

Paul is a qualified nurse and has a spinal injury following a motor vehicle accident whilst working in the Democratic Republic of Congo. He is also involved in carrying out disability awareness amongst established local HIV and AIDS organisations and is currently undertaking his PhD in Education, looking at the construction of sexual identity amongst youth with disabilities in rural South Africa.

Arne Fritzson

The Rev. Dr. Arne Fritzson is a pastor and theologian of the Mission Covenant Church in Sweden. He has written extensively on the area of systematic theology.

Joseph Galgalo

The Rev. Prof. Joseph Galgalo is the Vice Chancellor of St. Paul's University, Limuru Kenya. He is also an associate professor in the Faculty of Theology at St. Paul's University. He teaches Systematic Theology.

Sammy Githuku

The Rev. Dr. Sammy Githuku is the Dean, of the Faculty of Theology of St. Paul's University, Limuru Kenya. He is also a senior lecturer in the Faculty of Theology at St. Paul's University. He teaches Old Testament and Africanist Studies.

Ndung'u John Brown Ikenye

Ven. Dr. Ndung'u John Brown Ikenye is a senior lecturer in the Faculty of Theology at St. Paul's University, Limuru, Kenya. He teaches practical theology.

Samuel Kabue

Samuel Kabue is an ordained elder of the Presbyterian Church of East Africa and the Programme Executive of Ecumenical Disability Advocates Network (EDAN).

Rachel Kachanje

Rachel is a member of Federation of Disability Organization in Malawi (FEDOMA) and is the Deputy Chairperson of Disabled People's International.

David Kiari

The Rev. David Kiari is an ordained minister of the Presbyterian Church of East Africa and is currently the Principal of Presbyterian University in Kenya. He has written extensively in the area of pastoral counselling.

Reuben Kigame

The Rev. Reuben Kigame is founder and director of Word of Truth Ministries and Managing Director Fish Media, Kenya.

Janet Lees

The Rev. Janet Lees is an ordained minister of the United Reformed Church and a speech therapist. She is an Honorary Lecturer at the University of Sheffield and an Honorary Research Fellow of the Institute of Child Health, University College London.

Wati Longchar

The Rev. Dr. A. Wati Longchar is the former consultant of ecumenical theological education for Asia and Pacific – a joint program of WCC and CCA. Currently, he is Dean of Theological Extension Programs of the Senate of Serampore College (University), Kolkata, India.

Ralphine Razaka Manantenaso

Ralphine is the Chairperson of Collectif des Organisations des Personnes Handicapées (COPH) which has 140 association members spread all over Madagascar and is currently the most important federation of persons with disabilities.

Phitalis Were Masakhwe

Phitalis Were is a well known writer and commentator on disability issues in Kenya. He is a Sociologist and has a physical disability.

Sebenzile Matsebula

Sebenzile is the Executive Director of African Access Holdings and has passion for the empowerment of marginalised sectors of the community. She has previously worked as Director in the Office on the Status of Disabled People in South Africa.

Esther Mombo

Prof. Esther Mombo is the Deputy Vice Chancellor (Academic Affairs) of St. Paul's University, Limuru Kenya. She is also an associate professor in the Faculty of Theology at St. Paul's University. She teaches Church History and Gender Studies.

Salome Muigai

Salome Muigai is a development consultant in gender and disability based in Kenya. She is also an educationist and has been involved in research and formation of networks around Africa that engage governments on advocacy issues.

Seezi Gidudu Balayo Nabende

The Rev. Seezi Gidudu is a pastor of the Church of Uganda and a board member of the National Union of Disabled Persons of Uganda.

Anjeline Okola

Anjeline Okola is a member of staff of the Ecumenical Disability Advocates Network (EDAN).

C. B. Peter

The Rev. C. B. Peter is a senior lecturer in the Faculty of Theology at St. Paul's University, Limuru, Kenya. He teaches Old Testament, Philosophy, Theology, Disability Studies, and Research Methodology. He is also a publishing and research consultant.

Kaganzi Rutachwamagyo

Mr Kaganzi Rutachwamagyo, from Dar-es-Salaam, Tanzania has headed the Disability Resource Centre and International Disability Centre (IDC). He is a prolific writer and renowned disability activist.

Joseph Shiroko

Joseph Shiroko is a Programme Coordinator at the Brian Resource Centre in Nairobi. He is the father of one 21 year old Brian from whom the Centre derives its name. The Centre accommodates and trains Deafblind persons and their families on practical, relevant and life sustaining skills to enable them fit in the community.

Josephine Sinyo

Josephine Sinyo is a Senior State Counsel in the Ministry of Justice in Kenya and a former Member of Parliament. She has been involved in the disability movement for a longtime and is the past chair of United Disabled Persons of Kenya.

Index of Personal Names

- Abraham, K. C. 57, 368
Alan 146, 147
Anderson, P. 226
Anderson, Robert C. 62, 64, 165
Aquinas, Thomas 49, 50
Atkinson, M. 227
Augustine, Saint 34, 43
Avalos et al 108, 109
- Baker** 203
Bankole et al. 223
Barth, Karl 38
Birdsall, K. 223
Blair, W. Daniel 61, 71
Bonnie, Selina 203
Brunner, Emil 36
Bryne 143
- Callet 319
Calvin, John 36
Campbell J. 23, 106
Chappell P. 233
Chaung 227
Chenu, D. M. 49
Christie, Dame Agatha 66
Clark, Elizabeth 51
Coleridge, P. 148, 149
Collins, et al. 225
Cooper, Burton 70, 74
- Cowans, Gordon 52, 53
Creamer, Deborah 69, 72
- Darwin**, Charles 258
Derksen, J. 374
Dolphin, Lambert 44
Donnelly 203
Driedger, Diane 247
Dutton, Brian 142
- Edwards**, K. 230,
Eiesland, Nancy L. 43, 58, 63, 68,
69, 74, 104, 161
Eitosa, Charles F. 65
Elwan 229, 231, 232
Epperly, Bruce G. 161
Erevelles, Nirmala 71
Erikson, Erik H. 256
Erickson, Millard 37
- Fenichel**, Otto 264
Fine, B. D. 267
Fine, Bernard D. 256
Finkelstein, Vic 10, 11
Fontaine, Carole 105, 107
Fritzson, Arne 73, 163
Francis, D. 224
Freire, P. 373
Freud, Anna 260

- Freud, Sigmund 249, 260, 264, 267
- Gabbard, Glen O.** 254, 260
- Gerkin, Charles V. 249
- Gilligan, Carol 257
- Govig, Stuart D. 70
- Grey, Susan 247
- Groce, N. 222, 225, 226, 227, 229, 230
- Gronemeyer 225
- Hanass-Hancock, J.** 228
- Harris et al 369, 370
- Helander, E. 169, 222
- Heumann, J. 144
- Hopper et. al 277
- Hull, John M. 41, 43
- Ikenye, Ndung'u J.B.** 251, 261
- Ingstadt, B. 229
- Isherwood, L. 69
- Jackson** 226
- Johannsmeier, C. 233
- Kabue, Samuel N.** 56, 73, 163
- Kaseba, C. 147
- Kelly 223
- Kisanji 364
- Kitchin, R. 226
- Klepp et al. 223
- Knowles 148
- Knudsen, Christine 276
- Kristensen 145, 147
- Kubler-Ross, Elizabeth 249
- Laura, Arntson** 276
- Leclerc-Madlala, S. 229
- LeVine, Robert A. 270
- Levinson, Daniel J. et al 256, 257
- Link, B. 232
- Loveliflife 224
- Luther, Martin 35, 36
- Macha, E.** 144
- Mandela, N. 373
- Mbiti, J. 363, 364, 365
- McWilliams, Nancy 253, 254
- Miles, S. 144, 145
- Miller, Donald E. 254, 255
- Miller, Patricia H. 258, 261, 262
- Milligan, M. 226
- Millon, Theodore 270, 271
- Moltman-Wendel, Elizabeth 69
- Moore, Burness E. 256, 267
- Morris, J. 153, 202
- Murray, S. 147
- Nelson, James B.** 69
- Neufeldt, A. 226
- Newman, Gene 70
- Nganwa et al. 225
- Nthamburi, Zablun 162
- Nolan, Albert 54
- Oliver, M.** 143, 233
- Parker, W.** 232
- Phelan, J. 232
- Philander, J. 225
- Philpott, Graham 106
- Poling, James N. 254, 255
- Prokes, Mary Timothy 69
- Rapuro, O.** 230
- Razafindramiandra, Moks 317

- Rimmensberger, N. 224
Robert, L. 450, 251
Robertson, P. et al. 226
Rogers, Carl R. 272
Rogers, E. F. 69
Roberts 379

Shakespeare, T. et al 203, 226,
228, 233
Sibers Schmidt, M. 229
Smith, E. et al. 227, 228
Spencer, Michael 287
Sprick, K. 227
Stone E. 147
Stuart, E. 69
Sunter C. 229
Sullivan, G. et al. 227
Swartz, L. et al. 225, 226, 228, 232
Sweeny 230

Tada, Joni Eareckson 70
Tan, Amanda Shao 55
Tataryn, M. 233

Taylor, Edward 368
Terrell, Vicki 101
Thatcher, Adrian 53
Tillich, Paul 272
Trasi, R. 230
Tomkins, S. S. 266
Tyson, P. 262, 267, 270, 450, 251

Verma, A. 143

Wallace 226
Ward, John C. 70
Webb-Mitchell, Brett 70
West et al, 97, 106, 108, 109
Whiteside, A. 229
Wilke, Harold H. 61, 62, 70, 166
Wolfensohn, J. D. 232

Yousafzai, A. 230,
Yousafzai et al. 225, 227

Zisser, A. 224

Index of Subjects

- Abandonment of Disabled Children 366
- Able God and the Disabled Body 41
- Access to Buildings 375
- Access to Education 375
- Access to Employment 377
- Access to Health 376
- Access to Information
 - Communication
 - Technology 351
- Access to Job Market 352
- Accessible to the Workplace 352
- Advocacy of Tanzanians with Disabilities 373
- Advocacy for Accessible Physical Environment 350
- Affects, Feelings and Emotions 266
- Assistive Devices/Technologies to Disabled People 154
- Attitudes towards Persons with Disability in South Africa 404
- Attitudinal Barriers in Disability and Sexuality 203
- Attitude Change towards Disabled Persons 118
- Attitude, Negative 357
- Attitude, Testimonies of Negative 360
- Bible, Applying CBS in Interpreting the 105
- Bible, People with Disabilities in the 105
- Blindness at Advanced Stage of Life 306
- Blind, Learning Materials for the 352
- Building Standards Act No. 103 (1977) 407
- Business, Types of 421
- Capacity Building Training 349
- Capacity to Experience and Express 263
- Capabilities, The Innate Human 262

- Case Studies of Theological Education and People with Disability 163
- CBS, Remembered Bible as Key to 108
- Challenges among Mentall and Physically Disabled Persons 204
- Child, Overprotecting the 367
- Christian Church Organisations 330
- Church and Disability 100, 181, 399
- Church, Disability and the 330
- Church, Incorporation Within the 331
- Church Members 119
- Church, People with Disabilities in the 414
- Church, Personal Experience with the 112
- Church Perception 171
- Church Service, Returning to Our 183
- Church, Social Integration and the 286
- Church Workers, Barriers and Challenges that May Face 191
- Communication Aspect 378
- Communication Barriers 131
- Communication Channels, Lack of Knowledge on Available 125
- Community, Considerations When Working with the 192
- Community, Possible Activities when Working with People with Disabilities in the 193
- Conflicts and Emergencies 386
- Conservative View 60
- Coping Methods among Traditional Communities 365
- Counselling Persons with Disabilities 301
- Counselling, The Need for 301
- Counselling, The Process 301
- Coupling of Persons with Disabilities 370
- Cultural Barriers 131
- Culture, Use of 269
- Cultural Practices 404
- Cultural Traditions, Current Status and Effect of 368
- Deaf Blind Disability 179
- Deafness Disability 309
- Dependency of Persons with Disabilities 70
- Dependency Syndrome 376
- Development, The Role of FEDOMA in 349
- Development (WID), Essential Concepts in Gender And Development Women in 210
- Disability 5, 79, 122
- Disability Aesthetic, Exploring a 76
- Disability and Actual Situations, Types of 321
- Disability and DPOs, Policy on 325
- Disability and Sin, Jesus' Attitude Towards 54

- Disability and the Elderly,
Ministry of Persons with
338
- Disability as Consequence of Sin
50
- Disability as Vicarious: Reflecting
on 76
- Disability: Beliefs About Causes
of 170
- Disabilities: Caring for People with
91
- Disability, Care Systems, and
Practical Theology 254
- Disability, Church Fathers and
People with 162
- Disability, Complex Living Human
Document: Multiple Faces
of 251
- Disability, Constitutional
Provisions on 394
- Disability, Early Church and
People with 161
- Disability from the Policy
Perspective 374
- Disability, History of 319
- Disability, HIV & Aids as a Cause
of 235
- Disabilities, HIV & Aids and
Orphans with 225
- Disability in Uganda Before 1987
388
- Disabilities, Jesus Reinterprets
93, 97
- Disability, Literature on 315
- Disability, Medical Definition of
317
- Disability, Medical Model of 384
- Disability, Medical Type of 275
- Disability, Mental 322
- Disability, Mission Christianity
and People with 162
- Disability, Models of 384
- Disability Movement, History of
346
- Disability, Redefining 70
- Disabled People's Organisations
327
- Disability, Physical 321
- Disability, Sexuality and HIV &
Aids 226
- Disability, Social Definition of
317
- Disability, Social Model of 384
- Disability, Social Type of 276
- Disability, The Bible and
Leadership for People with
158
- Disability, The Socio-Cultural
Objectification of 63
- Disabilities, True Causes of 318
- Disability, True Causes of 174
- Disability, Visual 323
- Disability, Women with 216
- Disabilities, Youth with 223
- Discrimination, Stereotype and
Stigma 172
- Divuseni: A Case Study 420
- Divuseni, The Women Behind 423
- DPOs and Collective Bargaining
371
- DPO, Formation of 389
- Early Church's Experience on
Disability 11
- Education 142, 354, 369, 408
- Education and Training 385

- Education, The Role of 223
- Effects of Attitudes and Barriers 291
- Employment 146, 386
- Employment, Discrimination in 87, 284
- Employment or Economic Empowerment 409
- Environment Improvement for People with Disability 353
- Environmental and Informational Barriers 204
- Evidence-Based Approaches 150
- Eyes, Cataracts in the 177
- Eye Hospital, Presbyterian Church of East Africa 178

- Fair Representation in the Society 215**
- Family Activities, Exclusion from 281
- Family, Parents' Reactions to Disability in the 175
- Family Responses: Personal Experience 176
- Family Stability 175
- Family, The Role of the 176
- Family, Value of Investing in the 189
- Flagship, The UNESCO EFA 144
- Function, Psychological Disability as Loss of 271
- Funds, Lack of 281
- Future Prospects of Tanzanians with Disabilities 380

- Gender balance in Malawi 353, 388**
- Gender Analysis in Creation 210
- Gender and Development (GAD) 211
- Gender and Persons with Disabilities 216
- Gender, Disability and HIV & Aids 228
- Gender Equity 213, 214
- Gender Mainstreaming 215
- Gender Relations 212
- God's Creation, Sin and Suffering "Outside" the Structure of 49
- God: Sin and Image of 52

- Handicap 5**
- Handicapped (MACOHA), Malawi Council for the 338
- Healthcare for the Disabled Persons 151, 387, 409
- Hearing Disabilities 83
- Hearing Disability, Discrimination Against People with 88
- Hearing Impaired, Barriers Affecting the 123
- Hearing Impaired, Unhealthy Beliefs About the 126
- Hearing Problems 178
- Historical Perspective in Psychoanalytic Theories of Human Development 256
- HIV & Aids 355, 387
- HIV & Aids Awareness 224
- Human Development, How to Avoid Disability at Various Stages of 302

- Human Functioning, Disability and Psychoanalytic Themes of 262
- Human Rights: Persons with Disabilities Participation 354
- Identity: Use of Gender 268
- Image: Functional Interpretation of the 38
- Images of Disabled Persons, Family and Society 264
- Image of God, Relational View of the 35
- Image, Towards a Spiritual Interpretation of the 40
- Impairment 4, 5
- Impairments, Disfiguration and Other Physiological 310
- Impairment, Hearing 324
- Impatience 134
- Importance of Understanding Causes of Disability 188
- Inclusive Education 351
- Inclusive Vocational Training 352
- Infanticide 365
- Information, Lack of 280, 283
- Institutionalisation 372
- Is Sexual Abuse an African Phenomenon? 206
- Issues of Accessibility 234
- Kenyatta National Hospital** 177
- Knowledge Gap 149
- Language Discrimination** 299
- Language, Use of Derogatory 90
- Laws, A Critique of the 398
- Lazarus, Link to 99
- Leadership, Challenges of 166
- Left-Handed, Discrimination Against the 90
- Left-Handedness 84
- Legislation 283
- Lessons Learnt 188
- Liberal View 62
- Living Environment, Creation of a 260
- Malawi, Education in** 340
- Malawi, Special Needs Education in 340
- Malfunctions, Other Psychological or Physical 311
- Management 373
- Manthipi Molamu 425
- Masingita Masunga 424
- Matshidiso Seboni 425
- Maturity, Types of Counselling Required in 306
- Media Bias 282
- Mental Disability 85
- Metapsychology as a Scientific Instrument of Inquiry and Intervention from the Beginning 269
- Microfinance, Sustainable 149
- Mind, Structure and Contents of the 264
- Misplaced Concern 132
- Mobility 133
- Mobility Hazards 128
- Models of Human Nature 258
- Modern Times, the Church in 14
- Montfort College 342

- Nairobi Parents, Social Support
 and the Creation of the 184
 National Health Act No. 61 (2003)
 409
 Negative Attitudes, Causes of 390
 Negative Attitudes, Steps Towards
 Removing 393
 Negative Attitude, Testimonies of
 Instances of 390
 NGOs, Role of 118, 291
 Normative Approach, Should We
 or Should We Not? The
 Disabling Error of 59

Old Testament Construal 332
 Opportunities, Denial of 135
 Our Disabling Aesthetics,
 “Sensual Beauty is Good”:
 65

Paradigm Shift 405
 Parity 214
 Participation, Exclusion from 19
 Parliamentary Representation 411
 Pastoral Care 300
 Pastoral Care and Counseling
 Psychology, Disability
 Change and Care: Borrowing
 a Leaf from 273
 Pastoral Care Minister 191
 Pastoral Care Ministry 190
 Paternalistic and Patronising
 Attitude 19
 Peer Pressure 182
 Perceptions, Effects of Such 173
 Perceptions, How to Change 173
 Perfectibility or Moral Creation 44
 Personality and Traits 270

 Personal Experience 98, 278, 334,
 356, 415,
 Physical Disability 80, 83
 Physical Disability,
 Discrimination Against
 People with 88
 Physical Healing, Emphasis on
 21
 Physically Impaired, Barriers
 Affecting the 126
 Players, Other 292
 Policy and Legislation 339
 Politics, Participation in 379
 Positive Change of Attitude,
 Benefits from 174
 Poverty 385
 Poverty Alleviation 353
 Poverty, Disability and HIV &
 Aids 231
 Present Concerns and
 Challenges 279
 Presumed Needs-Based
 Exclusion 127
 Primary Schooling 279
 Productive Work 213
 Projects 422
 Protestant Church 400
 Psychology 264
 Psychological Development 256
 Psychosocial Disability 275
 Public Awareness 117, 283
 PWDs 4
 PWDs and Their Major
 Concerns, Vulnerability of
 385
 PWDs, Challenges Faced by
 357, 403

- PWDs, Church's Involvement in the Welfare of 342
- PWDs, Cultural Practices that Affect 393
- PWDs, Demographic Data on 344
- PWDs, Economic Empowerment of 414
- PWDs in Madagascar and Their Rights 324
- PWDs, Perception of 171
- PWDs, Perspectives on 299
- PWDs, Public Policy and Legislations for 405
- PWDs, Situational Analysis and Demographics of 297
- PWDs, The Code of Good Practice on the Employment of 410
- PWDs, The Impact on 412
- PWDs, The Negative Attitude toward 390
- PWDs, The Technical Assistance Guidelines (TAGs) on the Employment of 410
- PWDs, Traditional Beliefs about 363
- PWDs, UN Convention on the Rights of 359
- Redefining Wholeness, Normalcy and Perfection 73**
- Rehabilitation, Community-Based 153
- Relationships and Relational Systems 265
- Reproductive Work 213
- Resource Centre, Creation of the 186
- Resource Centre, The Brian 186
- Right and Wrong, Use of Reality, 267
- Rising to the Challenge of Disability and HIV & AIDS 236
- Role of Community Based Rehabilitation 236
- Scriptures, Attitudes towards People with Disabilities in the 86
- Sex vs Gender 211
- Sexuality, Barriers Preventing Women and Men with Disabilities from Expressing Their 203
- Sexual Division of Labour 212
- Sexual Development 264
- Sexuality, Family and Children 358
- Sign Language and All Saints Cathedral 183
- Sin and Disability 50
- Social Challenges 170
- Socialisation 125
- Social Integration, Barriers to 281
- Social Justice 215
- Social Obstacles 129
- Social Participation 16
- Social Security 387
- Societal Attitude 282
- Societal Perceptions 201
- Speaking Disabilities 82
- Special Needs Education (2001), White Paper 6 on 408
- Speech Disability, Barriers Affecting Persons with 134
- Spiritual Guidance 189

- St. Christopher's Deafblind Unit
in Kilimani 185
- Statement of the Problem 122
- Stereotyping 124
- Street People 280
- Stigma in Disability vs HIV &
AIDS 232
- Stigmatisation 281
- Suffering and Disability 56
- Superstitions 48
- Support from Members,
Reasons for Lack of 192
- Synthesis 278

- The Birth of Brian 176
- The Church and the Disabled,
A Historical Perspective
113, 114
- The Church's Response 339
- The Constitution of the Republic
of South Africa No. 108 of
1996 406, 407
- The Family Social Challenges and
Response to Disability 175
- The Employment Act 2006 397
- The Employment Equity Act No.
55 (1998) 409
- The Equal Opportunities
Commission Act 2007 397
- The Image and Likeness of God:
Traditional Interpretations
Reconsidered 33
- The Image of God: A Substantive
Interpretation 33
- The Integrated National
Disability Strategy (1997)
408
- The Issues Facing PWDs 357

- The Local Government
(Amended) Act 2001 398
- The Marriage Institution 172
- The Mental Healthcare Act No.
17 (2002) 409
- The National Building
Regulations 407
- The New Testament 159
- The New Testament approach
333
- The Old Testament 158
- The Policy on Disability 398
- The PWDs Act 2006 397
- The Preferential Procurement
Policy Framework Act No.
5 of 2000 411
- The Promotion of Equality and
Prevention of Unfair
Discrimination Act (2000)
408
- The SABS 0400 Code of Practice
407
- The Skills Development Act No.
97 (1998) 410
- The Social Assistance Act No.
13 (2004) 406
- The Use of Defenses 259
- The Way Forward: Some
Recommendations 77
- Theology of Disability 69
- Thoughts, Cognitive Ability and
Use of 267
- Traditional Beliefs About
Disability 316
- Treatment, Discrimination in 285
- Types of Disabilities Mentioned
in the Scriptures 80

Understanding Depression 277

Unemployment, Causes of 147

Universal Access to Persons
with Disability 407

‘Virgin Cleansing’ Belief 227

Vision and Mission of Divuseni
to South African Society
421

Visual Disability 81

Visual Disability, Discrimination
Against People with 87

Visually Impaired, Barriers
Affecting the 130

Withdrawal and Denial 179

Word of God, Accessibility to
the 117

- A Guide to Ethics* by Joseph Njino (2008)
- Pastoral Theology: Rediscovering African Models and Methods* by Ndung'u John Brown Ikenye (2009)
- The Royal Son: Balancing Barthian and African Christologies* by Zablon Bundi Mutongu (2009)
- AIDS, Sexuality, and Gender: Experiencing of Women in Kenyan Universities* by Nyokabi Kamau (2009)
- Modern Facilitation and Training Methodology: A Guide to Best Practice in Africa* by Frederick Chelule (2009)
- How to Write a Winning Thesis* by Simon Kang'ethe et al (2009)
- Absolute Power and Other Stories* by Ambrose Rotich Keitany (2009)
- Y'sdom in Africa: A Personal Journey* by Stanley Kinyeki (2010)
- Abortion and Morality Debate in Africa: A Philosophical Enquiry* by George Kegode (2010)
- The Holy Spirit as Liberator: A Study of Luke 4: 14-30* by Joseph Koech (2010)
- Biblical Studies, Theology, Religion and Philosophy: An Introduction for African Universities*, Gen. Ed. James N. Amanze (2010)
- Modeling for Servant-Leaders in Africa: Lessons from St. Paul* by Ndung'u John Brown Ikenye (2010)

Disability, Society, and Theology: *Voices from Africa*

This compendium of intensive research into various interfaces between disability, society and theology embodies the proceedings of a Workshop on Disability held at Mombasa, Kenya in June 2008, under the joint auspices of Ecumenical Disability Advocates Network, Nairobi, Kenya and St. Paul's University, Limuru, Kenya

The contributors are disability-specialists from all over Africa and one from India.

The book is meant as a major text in Disability Studies, especially from an African theological perspective.



Zapf Chancery

